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# NATURE AND MEANING OF OCCUPATION FOR YOUNG MEN WITH TETRAPLEGIA LIVING ON THE CAPE FLATS

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For
MSc(Occupational Therapy)

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DECLARATION

I, HILARY JANE BEETON, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise), and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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## ABSTRACT

In this qualitative study, in-depth interviews with three young men with tetraplegia, who have resumed living in their pre-injury environments on the Cape Flats, were used to uncover the meanings they attach to their everyday occupations. The aim of the study was to gain a deeper understanding of the nature and meaning of their occupations. Themes which emerged from an inductive analysis of the data: "It's a boring life", "Feeling trapped" and "Struggling to find a way", indicated that the most prevalent experience of occupation, was its limited and monotonous repertoire. Contextual barriers served to restrict opportunities for meaningful occupation. However, tentative meaning making through occupational strategies was evident. Occupations supporting meaningful relationships were highly valued in the absence of physical capacity. The contribution of occupation to re-defining self identity following a major life disruption, was discovered in relation to the themes. The findings have implications for clinical practice aimed at enabling occupation and for policy development.

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# Section 1

# INTRODUCTION

SECTION 1:

## 1.1 Introduction

The assumption of occupational therapists and occupational scientists, amongst others, is that humans are occupational beings and, as such, have a primary need to participate in life through engagement in productive and personally meaningful activities and roles. If it is occupation that defines the lives of human beings, then it is through engagement in occupation that we express who we are, what is of value to us, and who we wish to be. The ability to 'do' or engage in occupation is central to quality of life (Mattingly and Fleming, 1994) and ***"the need to engage in purposeful occupation is innate and related to survival"*** (Wilcock, 1993: 17). Wilcock believes that occupation provides the mechanisms for people to develop their natural capacities, to adapt to environmental changes, and to flourish and develop as individuals. Engagement in occupation is believed to be essential to living and to have the potential to influence health and well-being (Polatajko, 1992). It follows that humans, through occupation, have the capacity to adapt in response to life's challenges and that they can shape their lives to be healthy and meaningful in spite of disease, impairment and disability.

That ***"health and well-being are closely related and linked with everyday life, with opportunity for personal development and with caring communities"*** (The Ottawa Health Charter, WHO, 1986), is being increasingly recognised with the world-wide shift towards a primary health care approach. The Charter (ibid) states that ***"health is created and lived by people within the settings of their everyday life; where they learn, work, play, and love. Health is created by caring for oneself and others, by being able to make decisions and have control over one's life circumstances, and by ensuring that the society in which one lives creates conditions that allow the attainment of health by all its members".*** The definition of health has thus shifted from

being seen as merely the absence of disease to one which looks at the physical, mental, and social well-being of the person and includes a focus on the individual's ability to function optimally in his or her environment.

### 1.1.1 Challenge for Rehabilitation

In the course of daily practice, rehabilitation professionals come into contact with many clients with disabilities, who apparently are not able to engage in their desired daily occupations to their own level of satisfaction. It seems that, with perceived and real obstacles to engagement in desired occupations, continuance of the self as an occupational being sometimes no longer seems feasible. A *"decoupling"* from the occupational side of self *"results in poor functional ability, ill-health and depression"* (Clark, Ennevor and Richardson, 1996: 374).

Because illness or disability threatens the ability to function optimally in one's own environment, the fundamental goal of rehabilitation is commonly stated to be the enhancement of the quality of life of the person with chronic illness and disability in the context of his or her social support group and environment (Hammell, 1995; Jette, 1993; Whiteneck, 1994), as well as community re-integration (Whiteneck, 1994). Community re-integration brings with it subjectively experienced feelings of health and well-being as a desirable outcome of rehabilitation.

**The challenge for rehabilitation professionals is to know and understand what constitutes a life of quality and satisfaction for a person with severe impairment and disability, and what makes existence, in spite of severe disability, meaningful and worthwhile.**

### 1.1.2 Enabling occupational performance

In an occupational therapy context, health and well-being are considered to be dependent on the successful performance of relevant occupations (activities, tasks and roles) in everyday life. Occupation is the means by which performance is actualised. Rehabilitation, in occupational therapy terms, can be seen as enabling occupational performance, within a complex transactional framework of intrinsic factors (such as abilities, skills, personality, values and motivation) and extrinsic factors (such as the built-up environment, social networks, cultural traditions and societal rules and expectations). This view of health, in the context of daily living, has been a distinguishing characteristic of occupational therapy since its inception early in the 20th century.

Wilcock (1999: 194), in linking the concept of health to occupation, hypothesised:

> ***"health is the outcome of each organism having all essential sustenance and safety needs met, and of having physical, mental and social capacities maintained, exercised and in balance. This is achieved through a range of occupations, through what people do day to day, which in turn depends on a level of health able to provide the energy, drive, and functional attributes necessary for such engagement."***

### 1.1.3 Contextual realities for people with disabilities

Many barriers to occupational performance inside and outside the home, such as lack of access to transport, sport and recreation facilities, and minimal employment opportunities resulting from lack of education and training, have been identified (Integrated National Disability Strategy, 1997). Occupational therapists and other rehabilitation professionals need a good understanding of what clients do in these circumstances, why and how they do what they do, what influences their occupational choices, and how they derive meaning from an environment which appears to be unsupportive of occupational

performance. For intervention to be really effective, it should be geared towards the contextual realities of the client.

### 1.1.4 Need for better understanding of occupation

Given the primary goal of rehabilitation and the ubiquitous presence of occupations in the day-to-day lives of people, rehabilitation professionals would do well to have a better understanding of the nature of occupation of their clients as it occurs in the natural context of their homes. A deep understanding of the nature and meaning of occupation, particularly as it relates to health and well-being, is required. From this it should be possible to develop improved strategies and interventions that will help clients who have impairments and disabilities, to gain the skills necessary for accomplishing goals or projects they wish to pursue. Public policy also needs to be guided in matters related to rehabilitation, health and occupation.

## 1.2 RATIONALE FOR THE STUDY

### 1.2.1 Problem statement

Within the ambit of my clinical experience working with individuals with severe disability, I believe occupational therapists do not have adequate knowledge of the true occupations of such clients who are living at home, particularly those of different race groups and economic circumstances. They do not have a good understanding of what it is like for individuals with severe disability not to be able to do what they want to do and how this influences their health and well-being. I believe without this knowledge and understanding, the thrust of occupational therapy in their rehabilitation, that is, to enable meaningful and purposeful occupational performance to support community re-integration, is diminished.

Rehabilitation services in the Western Cape are largely institution-based. The focus of most in-patient rehabilitation programmes is on alleviating impairment, providing education on prevention of secondary complications and on mastery of basic and some instrumental activities of daily living. Some attention is given to psychosocial and occupational issues resulting from permanent impairment and in relation to pre-morbid occupations, life roles and lifestyles. There is, however, no real emphasis on understanding, from the perspective of the individual with disability, how he or she actually experiences everyday living with the things he or she can do and cannot do, especially after discharge. In the face of urgent health and basic health care needs in a budget driven service, occupational needs are not seen as a priority in rehabilitation.

My concern is that many patients with severe disability are being discharged from institution-based rehabilitation to their homes, ill-prepared to engage in community living. There are relatively few rehabilitation professionals (i.e. occupational therapists and physiotherapists) in the Western Cape who work outside institutions. For example, there are currently four community occupational therapists employed in the public sector in the Metropole, and a further three employed by non-governmental organisations (Personal communication: Western Cape Occupational Therapy Executive Committee, 2000). They are faced by a paucity of material and physical resources in attempting to manage post-acute rehabilitation of clients discharged from in-patient settings. The consequence is that the majority of clients do not have access to community based rehabilitation services after discharge from in-patient settings and receive minimal follow-up at any level of health care. This is further exacerbated by transport difficulties, particularly for those clients with severe mobility difficulties (National Rehabilitation Policy, 1998: 3-4).

A further problem surrounding current rehabilitation services in the Western Cape is that the service providers, who are responsible for designing the rehabilitation programmes,

have generally had little exposure to the values, social practices and life experiences of the majority of the service recipients. Historically, apartheid has served to isolate different ethno-cultural groups. The majority of the rehabilitation professionals currently belong to the so-called privileged, more educated minority group, while the majority of the clients are from the group which, in the post-apartheid era, continues to suffer economic and educational deprivation. Poverty, unemployment, overcrowded and inadequate housing, lack of community facilities and infrastructure, are a reality in the lives of a great many people with severe impairment who are discharged home to their own communities.

This study has focused on persons with spinal cord injury as they are a relatively homogeneous group who have one thing in common: the disability penalises them, often suddenly and dramatically as a result of sudden trauma, thereby reducing their opportunities to engage their former occupations. They must learn new types of recreation and leisure time activities and, perhaps, a new vocation. Tetraplegia as a result of traumatic spinal cord injury is considered to be one of the severest forms of disability (Trieschmann, 1988). There is one spinal cord injury rehabilitation unit in Cape Town, which caters for spinal cord injury survivors throughout the Western Cape.

### 1.2.2 Purpose of the study

The study was aimed at gaining a better understanding of the nature and meaning of everyday occupations and the role occupations play in the lives of men with acquired cervical spinal cord injury within the context of their own families and communities. Although the findings of this qualitative study cannot be generalised, the understanding generated by the data should sensitise, guide and inform rehabilitation professionals by providing an increased awareness of relevance of the life-world of these clients. With an improved understanding, occupational therapists should be more able to support patients' capacities for engaging in occupations and resuming a meaningful lifestyle. This is with

the assumption that engagement in occupations positively influences health and well-being. As such, meaningful occupation should be given a central place in the rehabilitation process.

By identifying what being occupied or not being occupied means to the individual with severe disability, the value of occupation would also be highlighted. Whether or not lifestyle support services for severely disabled people living in the community need to be established, will become known. This should serve to inform policy makers and funding providers of the value of occupational therapy services in the community.

### 1.2.3 Aim of the study

This study is aimed at exploring and constructing an understanding of the lived experience of the daily occupations of young men with tetraplegia resulting from traumatic spinal cord injury. It was based on the premise that engagement in occupation is essential to the meaning of life and that occupation has the capacity to influence health.

### 1.2.4 Objectives of the study

The objective of the study was to gain from the perspectives of the informants an understanding of the nature of their everyday routines, activities and occupations, that is, what do they do and how do they do it.

1. Explore what meaning they ascribe to their experience of everyday occupations and to what they are unable to do.
2. Highlight contextual factors that they feel support or do not support their occupational engagement.
3. Gather evidence on how occupation serves adaptation.

# Section 2

# EVOLUTION OF THE STUDY

## SECTION 2

## EVOLUTION OF THE STUDY

In order to describe the evolution of this study in more detail, it was necessary for me to examine my assumptions, either as they arose from my personal understanding of occupation or from what I had gleaned from the occupational therapy and the occupational science literature. I also reviewed literature on spinal cord injury where this impacted on occupation and vice versa

.

### 2.1 What do we understand by the term occupation?

The word occupation is understood differently by different people. For some it is equated with simple activity; for others it means productive behaviour or work. However, the common threads running through the occupational therapy literature attribute a much broader meaning to the word 'occupation'. Occupations are described as the pattern of activities in which people engage every day and which can be described to others (Clark, Parham, Carlson et al, 1991). Christiansen and Baum (1997), citing from the occupational therapy literature, further emphasise that occupations engage resources of time and energy, are purposeful, and are culturally meaningful, and done in the context of one's physical and social world. Occupations are multidimensional as they involve physical, affective, cognitive, symbolic, socio-cultural and spiritual aspects and hence are laden with meaning for the doer. Occupations thus have both performance and personal meaning dimensions. They are defined subjectively by the individual for meaning and purpose in a socio-cultural context.

The definition of occupation, used by Law, Steinwender and Leclair (1998: 83) appears to encompass the most important characteristics of occupation. Occupation is defined as

> ***"... groups of activities and tasks of everyday life, named, organised, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)."***

Yerxa, Clark, Frank, et al (1990: 9) maintained that the meaning dimension of occupations is critical to understanding occupations as that which relates to health and well-being. They maintained that " ***to fully understand occupation, it is necessary to comprehend the experience of occupation....The same occupation may have a myriad of different meanings depending on the goal of the individual, the environmental context, or mood."***

## 2.2 Personal reflections on occupation

As an occupational therapist, my interest in community living and quality of life issues has developed out of my interactions with clients with severe impairments who live at home. My observations of the barriers to and limitations in opportunity to engage in what I perceive to be interesting, worthwhile and productive occupations (activities), has left me with a feeling of impotence in my clinical practice.

This has been compounded by my observation of the home contexts of many of my clients. These seem unsupportive and sometimes hostile and counterproductive to any meaningful occupational engagement. The apparent passivity and resignation of the person with a severe disabling condition living in poor socio-economic conditions was not

difficult for me to understand from my middle class perspective, as I too identified my own feelings of disempowerment in the situation. However, I had difficulty reconciling this with my typically protestant middle class belief that hard work, and motivation to help yourself, should bring its own rewards.

In contrast to some of these demoralising experiences, I have also witnessed the personal transformation of individuals with severe disabling conditions through their involvement in Sport for Physically Disabled Association. This has convinced me of the personal and social transformation potential of meaningful occupational engagement in valued occupations. It has led me to renew my questions around the experience and meaning of occupations in everyday lives and about what supports or limits occupational engagement for individuals with severe impairment.

With the move to reclaim occupation as the core organising construct of occupational therapy, there has been a burgeoning of reading material available about the subject. My reflections on my clinical practice and my concerns about the effectiveness of occupational therapy in contributing to quality of life for people with chronic illnesses and disabilities, especially those suffering socio-economic hardship, has forced me to enter the debate on a personal level.

My own tenet that meaning in life is to a large extent derived from what we do and how we relate to the people around us, is supported in the occupational therapy and occupational science literature. The literature has awakened me to the conceptual complexity of occupation, but three fundamental assumptions guided this study initially:

- that health and well-being are linked to involvement in meaningful occupations,
- that everyday occupations bring meaning and coherence to existence, and

- that "*human beings constitute themselves through their occupations; they evolve as occupational beings and evolve into who they shall become through their immersion in their daily practices, habits and activities*" (Clark, Ennevor and Richardson, 1996: 375).

I began to reflect more and more on my feelings of inadequacy when facing clients with severe disability who had returned to and were living under difficult conditions in their own communities. Some were questioning the meaning of life in the face of not being able to do what they wished to do. They were frustrated because they were unable to do those things that previously had contributed to their sense of self within their families and communities. Others seemed happy to just 'be at home'.

My observations and reading had demonstrated to me that, despite overwhelming odds, some severely disabled individuals were able to overcome life's obstacles through negotiation and creative solutions. The development of the self as an occupational being could continue albeit in a different way. In other instances, individuals, with the loss of ability to engage in previously valued and meaningful occupations, sank into a lethargy and passivity, and seemingly experienced a corresponding loss of health and well-being. The latter were frequently labelled by health professionals as lacking in motivation.

What made the difference? How could I as an occupational therapist really enable a meaningful occupational life if I had no real understanding of what it was like to live with severe disability or chronic illness? How was I to understand these restrictions to occupational engagement imposed, not only by the nature of the disability or illness itself, but also by contextual issues such as an inhospitable environment, lack of finances, and unreliable and expensive personal assistance? It felt to me that occupational engagement was restricted at every level. Chronic illness and disability had made more

visible the obstacles imposed on them by poverty and poor socio-economic conditions (which many of them had experienced throughout their lives and in the development of themselves as occupational beings prior to my contact).

As an occupational therapist I needed to understand the role of occupation in the lives of these people. Hopefully then I could help them to mediate a major life disruption of sudden disability and consequent loss of physical ability and the concomitant loss of roles, lifestyle and preferred occupations.

### 2.3 Contextualization of the study within the framework of my clinical practice

Against the backdrop of my clinical practice in the public health sector, I chose to study the occupations of a group of individuals with severe impairment and disability who came from relatively similar backgrounds to many of my clients. I chose to study the occupations of a group of individuals who had suffered not only a major disruption in their lives, but who were doubly disadvantaged in the sense that they lived in poor socio-economic circumstances. I decided that I would begin by looking at individuals with tetraplegia resulting from traumatic spinal cord injury as they formed a relatively homogeneous grouping.

Tetraplegia is, arguably, one of the severest forms of physical disability. It disrupts a wide range of an individual's established patterns and routines of daily living as well as future goals and expectations. The incidence of traumatic spinal cord injuries reflects the primary causes (gunshots, stabbings, motor vehicle accidents, sport-related injuries and industrial accidents)(Trieschmann, 1988; Appendix 1: Admissions to Spinal Cord Injury Unit at Conradie Hospital during 1999), with men being involved four times as often as women (Trieschmann, 1988). Similarly, it is more common in active young men, with the mean age of injury being at about 29 years, with half being injured before the age of 25

years (Scherer, 1993; Trieschmann, 1988). It occurs at a time of life that is often considered to be the most economically productive, although this might not necessarily be the case in South Africa, with its high rate of unemployment.

I needed to understand how and what these men really did in their difficult circumstances and what meaning they attributed to what they did.

### 2.4 An overview of functional outcome of cervical spinal cord injury

The causes of spinal cord injury (hereafter referred to as SCI) are many, but basically fall into two broad categories, namely pathological (such as spinal tuberculosis, transverse myelitis and tumours), and traumatic (originating from gunshot wounds, stabbings, motor vehicle accidents, diving accidents, falls and sport injuries).

Although it is a physical phenomenon, SCI has far-reaching consequences for the individual in all domains of everyday living. Loss of mobility, sensation and object manipulation, as well as bladder and bowel control, and sexual dysfunction impact on all life spheres, namely personal management, social and life roles, leisure, and vocational pursuits. A brief overview of the consequences of SCI at cervical vertebral level (hereafter referred to as C plus the number of the vertebral level of the lesion), is given here as background for this study.

According to Scherer (1993), it is rare to have survivors of spinal cord injuries at or above levels C3 and C4 segments. An individual with function preserved at a C4 level, is essentially paralysed from the shoulders downwards with very little or no sensation or motor function below the level of the injury. Persons with injuries at C5 and C6 levels can be expected to get themselves in and out of their wheelchairs with some personal or mechanical assistance and can drive a car with special hand controls and other adaptive

equipment. Individuals with function preserved at C6 level, may be able to perform some crude grasping activities, but continue to need assistance with transfers, some aspects of dressing, feeding and bathing. Those individuals with C7 and C8 level lesions, are able to work with their hands independently, and with their functional triceps muscles and should be able to transfer in and out of their wheelchairs independently. While an individual with a C8 level lesion should be independent in most self-care activities, an individual with a C7 level lesion may still require some assistance, whether it be mechanical or personal. Spinal cord injuries may be complete or incomplete with the functional outcome being determined by residual intact motor and sensory pathways.

Notwithstanding the level of lesion, the consequences of spinal cord injury are unique to every individual. Similar injuries may not result in exactly the same losses of motor function and sensation, and individuals react and adjust to their injuries in different ways and over varying lengths of time (Trieschmann, 1988; Scherer, 1993). Studies have shown that there is no relationship between level of injury and quality of life, or between physical independence and quality of life, following spinal cord injury (Fuhrer, Rintala, Hart, et al, 1992). Quality of life must therefore be dependent on factors other than physical skill, and the degree of satisfaction with life when returned to the pre-injury environment must be attributed to factors other than impairment (Hammell, 1995).

## 2.5 Literature review

### 2.5.1 Occupation in major life transitions

I was essentially setting out to understand the nature and meaning of occupational engagement during a period of great transition with the underlying assumption that occupation and its personal meanings are central to major life transitions (Blair, 2000). 1-

5 years is commonly cited as the period required for adjustment to living with SCI. Fundamental assumptions were that:

- Occupations are impacted on by life transition and may change, be disrupted temporarily or be discontinued (Blair, 2000).
- Engagement in meaningful and valued occupations facilitates adaptation in periods of transition (Schkade and Schultz, 1992; Blair, 2000).

Literature on SCI acknowledges that for the survivors, this transition requires adjustments and adaptation in terms of role changes, disruption, discontinuation or a change in balance of valued occupations (Trieschmann, 1988; Hammell, 1995). The effect on self-esteem and self-concept induced by interrupted life stories has been well described in both the popular press and social science literature. Blair (2000: 231) cites Adams et al (1976) in describing transition as "**a discontinuity in a person's life space.**" Everyday living is altered in terms of routines, habits and a previously taken-for-granted configuration of occupations. Personal responses to transitions differ from individual to individual but all require some sort of personal reappraisal within the changed circumstances. Popular press (Reeve, 1998; Hurley, 1983; Thomas, 1994) has tended to portray positive adjustment to disability and hardship, but this is not always evident in day-to-day clinical practice.

The challenge for occupational therapists is to capture and nurture the will to manage change as the very essence of therapy (Blair, 2000) and to reaffirm the client with chronic impairment and disability, however severe, as an occupational being, in whatever way possible.

### 2.5.2 Occupation contributes to life satisfaction and improved quality of life

In the numerous studies on community re-integration for people with spinal cord injuries, methodologies vary. Generally they have been empirical in nature, using measures of function (e.g. FIM, Barthel Index), handicap (CHART), depression, life satisfaction (on questionnaires and Likert type scales) and time budget methodologies and activity profile questionnaires. (Refer to Appendix 2: Abbreviations and Explanations of Tests Listed.) Most studies exploring variables which relate to life satisfaction, health and well-being, consider occupation as one of the dependant variables (Whiteneck, Tate and Charlifue, 1999; Fuhrer, Rintala, Hart et al, 1992; Dijkers, 1999).

Life satisfaction among people with spinal cord injuries has been found to be significantly related to social integration, mobility, occupation, social support, perceived control and self-assessed health status (Fuhrer, Rintala, Hart et al, 1992). Greater life-satisfaction was associated with the lesser handicap in the three dimensions of handicap: social integration, occupation, and mobility. Specifically, somewhat greater life satisfaction was reported by persons with spinal cord injury who were doing more to maintain customary social relationships (social integration), spending more time in ways customary with the individual's gender, age, and culture (occupation), and moving about more in their surroundings (mobility) (ibid).

Law, Steinwender and Leclair (1998) did a critical research literature review examining the relationship between occupation, health and well-being. The review covered research both inside and outside the field of disabilities. Although their findings produced moderate to strong evidence that there is a strong correlation between these concepts, they could not support the premise that enjoyment in occupation causes health and well-being. In their conclusion, they cautioned that health is complex and defined differently by individuals. They noted that, because measures are seldom standardised in research,

by individuals. They noted that, because measures are seldom standardised in research, it is important that health workers learn from each client what occupations are important to his or her health and well-being, and how current problems interfere with the performance of occupations meaningful to him or her as an individual.

Do Rozario (1997), using a phenomenological and heuristic research design, listened to and analysed the life stories of 45 people with disability and chronic illness. Her analysis confirmed for her that meaningful participation in activities and life, was one of five key factors that helped to facilitate health and well-being, the others being power of hope, power of personal contact, positive social support, and the journey of spiritual reconciliation and transformation. She felt these factors were interdependent.

If we are to believe that engagement in meaningful occupations and fulfilling activities is a prerequisite for quality of life, and perhaps even for survival itself, it must be hypothesised that life without occupation and stimulation may lead to loss of meaning of life and ultimately to despair. The well-known story of Nancy B. epitomised this (Polatajko, 1992: 190). Paralysed from the neck downwards following Guillain-Barre Disease, she begged to be allowed the right to die. As she put it to the judge: ***"This is not a life...I do not want to live. The only thing I have (to do) is television and to look at the walls."*** She had lost all meaning in everyday activities and in life itself.

### 2.5.3 Occupation constitutes use of time

The basic assumption that occupation constitutes a use of time, irrespective of what that occupation is, is supported in the occupational therapy and occupational science literature. Humans, as occupational beings, have a need to use time in a purposeful way.

There has been relatively little research on how people with severe disabilities occupy their time, especially those with severe mobility and hand use limitations. It is not clear how they feel about it, or what the relationship is between their activity patterns and their feelings of well-being. There has been more research internationally on time use, particularly in gerontological and leisure studies, for non-disabled people. No research into time use in South Africa was traced.

Studies on the configuration of occupations and time use have made attempts to describe the manner in which daily activities could be viewed in a pattern which characterises a person's lifestyle and life story.

Pentland, Harvey and Walker (1998) explored, in a cross-sectional study design, the influence of severity of disability, socio-economic status and social support on the time use of 312 men with SCI, and the effect of all of these on their health and well-being and adjustment to disability. Their findings indicated that the amount of time spent in the four occupational categories of self-care, leisure, productivity and sleep did not appear to have a predictive linear relationship with psychosocial outcomes. They did establish, though, that perceived satisfaction with time use impacted on psychosocial outcomes of life satisfaction, perceived health and adjustment to disability. As a result, they hypothesised that the contextual intrinsic aspects of time use, namely meaningfulness, challenge and satisfaction override objective time use, and that even a little time in a highly satisfying activity may compensate for time spent in less satisfying activities and be more predictive of health and well-being. Their findings further indicated that time use did not appear to be significantly influenced by disability severity, socio-economic status or by social support. Morgan and Jongbloed (1990), in contrast, found that the quality of relationships with family and friends (social support) did positively influence engagement in social and leisure activities after acquired disability (stroke). It is my assumption that all three, i.e.

disability severity, socio-economic status and social support, do impact on occupational time use and configurations.

Yerxa and Baum (1986) found that the patterns of engagement in daily activities of 15 individuals with SCI living in the community differed in comparison to 12 age and sex-matched cohorts. Despite the small sample, time-use of the SCI group was different to that of the non-disabled group. They spent less time (though not statistically significant) in subjectively categorised self-maintenance, considerably less time in work, a little more time in rest, similar amounts of time in sleep and play, and considerably more time (statistically significant) in other activities. This category included everything perceived by the subjects not to fall into any of the previous categories, with activities such as watching television, sorting mail, reading the Bible being delegated to this category. It was concluded that less time was spent on self-maintenance and home management skills because these had been eliminated or reduced in the activity configuration by delegation to others – attendants or family members.

### 2.5.4 Balance in occupations

Closely related to time use, a further basic occupational therapy assumption about occupation is that there is the need for balance in the configuration of daily occupations. If active involvement and participation in a variety of activities and roles has been shown to positively affect health and well-being, it is logical to assume that an inability to participate in occupations, or a paucity or an imbalance in occupations may negatively influence quality of life.

Meyer (1977) recorded that, as early as 1922, he recognised that balanced, varied, and purposeful use of time was both health maintaining and health generating. Yerxa (1998) added to this in her observations that the experience of occupations and their unique mix

in life routines contributes to the shaping of a person's perception of the quality of his or her life.

Kielhofner (1977: 238) postulated that ***"it is the interrelated balance of self maintenance, work, and play that comprises health"***. A key premise of occupational therapy has been that ***"a person who manages to perform or have performed those occupations which facilitate health maintenance, provide for basic needs, and perform leisure pursuits, is more likely to achieve a state of health than a person who does not"*** (Reed and Sanderson, 1983: 63).

### 2.5.5 Satisfaction with performance contributes to life satisfaction

Linked closely with overall life satisfaction, is satisfaction with actual occupational performance. Various studies have considered the subjective experience of a specific disease or impairment in relation to engagement in occupations.

Satisfaction with performance in two particular areas, namely home management and social / community problem-solving skills, were found to be statistically significantly lower in their SCI sub-sample by Yerxa and Baum (1986) than in the matched non-disabled sub-sample, and correlated with overall lower life satisfaction of those with SCI. Yerxa and Locker (1990) demonstrated, in a content analysis of the data of the 1986 study, that the affective quality of particular occupations seemed to relate to the affective quality of the entire day. This supported the relationship between satisfaction with occupations and a more general satisfaction with use of time.

Other studies have supported ***"that a person's capacity to sustain meaningful and realistic occupational roles, is closely associated with his or her general satisfaction with life"*** (Bränholm and Fugl-Meyer, 1992:169). Stanley (1995), in her

study on a non-disabled population (elderly South Australians), indicated a positive relationship between engagement in meaningful occupation and social occupation, and health and well-being. She cautioned that the average duration of time spent in an occupation could not be assumed to directly reflect the value of that occupation for the individual. Health, socio-economic status and perceived satisfaction with health did not apparently have a significant relationship with engagement in occupation. However, there was a positive correlation between participation in social occupations and increased life satisfaction. Wilcock, van der Arend, Darling et al (1998: 76) concurred with her findings.

### 2.5.6 Occupational engagement is influenced by contextual issues

There is an increasing awareness that the environment plays a role in determining occupational performance. Law (1991: 174) reminds us that ***"all occupation is performed within a context".*** She defined environments as those ***"contexts which occur outside individuals and elicit responses from them".*** Environments can both hinder and support satisfactory engagement in occupation.

Letts, Law, Rigby et al (1994) did a review of environmental assessments which address models of person-environment interaction. They highlighted the importance of considering the person in interaction with his or her environment and that people's subjective experiential perceptions of the environment (physical, social, attitudinal and organisational factors), influence this interaction. Trieschmann (1988) concurred with this. She suggested that, historically, much emphasis had been placed on the personal resources of the individual with disability, in overcoming obstacles to achieve community re-integration. One of her major premises was that the human is a system that constantly strives to achieve a balance among three major influences in life – namely psychosocial,

biological-organic, and environmental, and that this premise should serve as a cornerstone of rehabilitation.

Research has documented that life satisfaction in SCI survivors is greater for those who are actively involved in productive activities and overall lower than for the non-disabled population. It has not been strongly related to injury severity or physical impairments, but rather to the ability to participate in activities and roles, and the influence of contextual factors on outcomes.

Richards, Bombardier, Tate, et al (1999) hypothesised that increased access to the environment would improve life satisfaction. Their findings suggested that being healthy, busy, and actively engaged inside and outside the home, are positively associated with satisfaction with life. However, the statistical procedures they used, could not clarify a causal relationship between occupation, life satisfaction and environmental access. The inference, however, is that access to the environment facilitates the ability to actively engage in meaningful activity of various sorts, which in turn yields greater satisfaction with life.

A study by Nosek and Walter (1998) concurred with these findings. They investigated the psychological, social, vocational and environmental factors affecting the community re-integration of disabled women. It was found that environmental barriers related to socialising, paid work and unmet needs for personal assistance services impacted on life satisfaction for this group. There was no difference in comparison to their non-disabled counterparts in elements of community integration related to relationships, personal and psychological resources. Differentiation of environmental barriers into physical, attitudinal and personal was not made, but further study was advocated.

The person-disability-environment interaction is also recognised in the ICDH-2 (WHO, 1999) as being important for participation.

### 2.5.7 Occupation, disability and poverty

I suggest that occupation as a human right receives little focus in lives of people with disabilities living in poor socio-economic conditions. Poverty has traditionally been defined in terms of a poverty line defined by income level or monetary value of consumption which separates the "poor" from the "non-poor" (Friedman, 1999: 3). However attempts are now being made to quantify poverty in relation to denial of basic socio-economic rights. Thus poverty is not only about a lack of money or material goods, but also about the absence of opportunities and choices which people need to build decent lives (ibid: 4). Poverty or poor socio-economic circumstances pose serious risk factors to health, which are only compounded by disability. It is my assumption that inappropriate or lack of access to meaningful occupations, called occupational deprivation by Wilcock (1998), poses yet a further threat to health for people with disability living in poor socio-economic conditions.

SCI research literature has indicated that SCI survivors living in poorer socio-economic circumstances (in the USA the minority groups), do have less access to resources which might limit occupational opportunities, than do their more financially well off counterparts. Cock (1989) describes the experiences of black SCI wheelchair users living in the economically depressed town of Soweto outside Johannesburg as being marked by poverty and social isolation as a result of severe environmental, economic, and attitudinal barriers. The descriptions provided in the research report have numerous examples of how occupation was restricted as result of these barriers.

# Section 3

# METHOD OF ENQUIRY

## SECTION 3 : METHOD OF ENQUIRY

### 3.1 RESEARCH DESIGN

The focus of this study was to gain an understanding of the occupations of individuals with severe impairment who were living in circumstances different from my own, and to 'feel', from their perspective, their situation. Thus phenomenology was chosen as the method of research because it focuses on the "lived experience". It helps the researcher to look at ordinary daily human life experiences in context in order to discover meaning (Munhall, 1994), with the understanding that the reality of ordinary life is defined by the perception of the person living it. The strength of this approach lies in the assumption that reality is constructed and interpreted by individuals, and that the way people behave depends how people make meaning of that reality. It is the subjectivity that expands and enriches the authenticity of the perceptions and understandings of phenomena. The meanings ascribed to these phenomena come from the individuals living the experience and therefore are not assumed or assigned.

The research design was used to gain an understanding of the nature and meaning of engagement in occupation. Study of the nature and meanings of occupations requires approaches that observe behaviours in natural settings and capture the unique stories, meanings and complexities of individuals' experience of occupations (Neistadt and Crepeau, 1998).

Starting at the point of the researcher's experience of the phenomenon and ***"travelling through other peoples' experience of it, the researcher eventually arrives at a general understanding of a phenomenon in its unique and essential manifestations"*** (Becker, 1992: 33).

Phenomenologists study everyday events or phenomena from the inside, from within the world of the person experiencing them, in order to understand their nature and structure. It is assumed that experience is a valid source of knowledge and that people's everyday experiences contain rich insights into the phenomena (Becker, 1992). The research informants are regarded as experiencing, reflective individuals, and the research situation is an interpersonal one in which the researcher and the informants are experiencing and co-creating meaning. It is the task of the researcher to capture meanings, summarise them into essential themes of understanding and capture the important aspects of the phenomena. The understanding of what something is, prefaces knowing what causes it and influences it. The phenomenologist aims to give plausible insights, rather than theory, into the experience of a phenomenon (Finlay, 1999).

## 3.2 SAMPLING

The sample was small and opportunistic, as is commonly found in qualitative research. Sampling continued until it was felt that no new information was being shared by the informants, that is, saturation had been achieved. Three informants were interviewed. Issues regarding data collection are addressed under 3.5.2.

It is recognised that each informant experiences the phenomenon in an essentially unique way and that the findings cannot be generalised (Miles and Huberman, 1994). Furthermore, Mason (1996) advocates that qualitative research should produce social explanations which are generalizable in some very broad way, or which may have a wider resonance. The representativeness to the broader population of interest by virtue of key characteristics (ibid) such as gender, age, residence and impairment were thus considerations in the sample selection criteria.

The following guidelines were used in selecting the informants:

- **Men with tetraplegia:** While I was interested in the phenomenon of occupational performance in all people with moderate to severe disability, it was felt that a more homogeneous group of one disability type would facilitate the study.
- **Living on the Cape Flats:** This criterion was chosen for three reasons: The majority of clients in my own clinical practice live on the Cape Flats, and it was my wish to understand their occupations; the area was easily accessible to me; and, most importantly, there is a high incidence of spinal cord injury resulting in paraplegia and tetraplegia in the Western Cape and more particularly on the Cape Flats in Cape Town. (See Appendix 1B and 1C.) This is considered to be a consequence of the high rate of violence (gang fighting) and road accidents in these areas. The Cape Flats describes a large geographical flat sandy region situated in peri-urban Cape Town. It is characterised by densely populated residential suburbs that vary in their socio-economic conditions from very low to low-middle class. The housing is predominantly small two to three bed-roomed free-standing homes on very small plots, or in densely populated three to four storey blocks of flats. Health, social and transport services are generally regarded as being inadequate. Gangsterism, alcohol and drug abuse, and unemployment are major social problems.
- **Aged between 18 and 35 years old:** The prevalence of spinal cord injury is particularly high in men falling into this age group (Scherer, 1993; Trieschmann, 1988). It was felt that the nature and meaning of occupations in young adulthood would differ from those in late adulthood.
- **Living at home:** The majority of people with disabilities are discharged from rehabilitation institutions to live with their families at home (Personal communication). Residential care caters only to a very small number of people with disabilities and indeed is not desirable, with increasing emphasis on the social model of disability.

- **Discharged from in-patient rehabilitation between one and three years previously:** I was primarily interested in informing policy makers of rehabilitation needs of individuals with severe impairment who have recently been discharged home and into the community. I felt that the first three to five years after injury are the years of greatest adaptation to living with the consequences of spinal cord injury. This was confirmed through personal communication with SCI survivors with whom I have had contact in the South African Sports Association for Physically Disabled and colleagues working with SCI survivors. I recognise that adaptation is a lifelong process and impacted by variables such as family support, age, environmental accessibility, etc. (Trieschmann, 1988)
- **All informants were required to speak English or Afrikaans:** Data collection and analysis in qualitative research depend on the ability of the researcher to understand and communicate with the informants. A translator for Xhosa informants could have been used, but time restrictions imposed by this study did not allow for this.

It was felt that a key informant interviewed after data collection, collation and interpretation would enhance the trustworthiness of this study. The criteria used in selecting this key informant were that he himself should be tetraplegic, living on the Cape Flats, and be articulate and able to reflect on the data and his own experiences.

### 3.3 NEGOTIATING ACCESS TO THE INFORMANTS

Association for Physically Disabled, Western Cape provided me with the names of six individuals, who appeared to fit the selection criteria for the study. All the informants were contacted in writing by the organisation to inform them of the study. I then made telephonic contact with each individual approximately three weeks later. Only two of the individuals fitted the sample criteria. I provided each with a very brief overview of the study (or spouse in one instance) on the telephone and made an appointment to see

each in his own home at a time to suit him. After analysis of the interviews of the first two informants, the names of a further two informants were provided by the Occupational Therapy Department at Conradie Hospital, after the potential informants had given their permission. After repeated attempts, I managed to make contact with only one to make an appointment for an interview.

### 3.4 INTRODUCTION TO THE INFORMANTS

As background, it is expedient to introduce the reader to the three research informants and the key informant who contributed to this study. Names of the research informants have been changed to preserve their anonymity. I have described the context in which Jon lives in more detail, to give the reader an example of my diarised observations and feelings at the time of the interviews. Space restrictions do not allow me to deal with all the informants in the same depth in this report.

3.4.1 **Jon**, at 30 years old, sustained a C5 spinal cord injury three years prior to the study. He is currently living in two different suburbs on the Cape Flats, an arrangement made to provide respite for his carers. He spends alternate weeks with his maternal grandmother, in Elsiesriver, the suburb where he grew up and lived prior to his spinal cord injury, and with an uncle and aunt, in Mitchells Plain, a suburb not previously well known to him. His grandmother, at 79 years old, continues to go out to work daily, as do both his uncle and aunt, for economic reasons. Although not married, Jon has two children, a son and daughter, who live with their respective mothers in Elsiesriver. He also has frequent contact with his girlfriend who is the mother of his daughter. She is a primary caregiver when he is staying with his grandmother in Elsiesriver.

In Mitchells Plain, Jon is assisted with his personal care activities daily by his cousin. In Elsiesriver, he is assisted by his girlfriend and a male friend. He prefers living in

Elsiesriver where he is both known and has friends and feels more supported. In Mitchells Plain, he knows only his immediate relatives and asserts that he feels alone and lonely. However, he recognises that a compromise is necessary as his grandmother is old and the flat very small. In addition the flat in Elsiesriver inaccessible, being on the second floor of a council block. He has to be carried down the steep narrow staircase by at least two friends to gain access to outside. The house in Mitchells Plain is more spacious and accessible.

I visited Jon three times in Elsiesriver. On entering the neighbourhood on a cold wet winter's afternoon, there were still people on the streets, children playing under the lines of washing in the courtyard of cracked uneven paving outside the block of flats – all the signs of a pervading poverty in the area. I was struck by the wheelchair inaccessibility as I entered the three-roomed flat via a steep narrow winding staircase, a gate and the front door with a 15cm high lintel. Jon was always in his wheelchair, positioned at the window of a small bedroom, containing basic furniture, a small TV and radio. There was no space to move, especially for someone in a wheelchair. Yet this was his preferred place of residence.

Jon seemed pleased to see me, instructing his helper / friend to help set up the recorder. The room felt awkwardly small as I sat on the bed. It was the only place to sit. There was not enough space to move the wheelchair around so that we could face each other for the interview. As Jon spoke, his overall body stillness, his soft monotonous tone and his general air of resignation reinforced my own feelings of restlessness and questions around the meaning of life when everyday living seemed so difficult. The apparent lack of control and stability in everyday living before and after his injury, related to living in an area where gangsterism, unemployment and poverty are rife, made me feel that there were few options open to him or others in his situation for engagement in personally

enriching occupations. His plea at the end of the interview, that I position his wheelchair at the window so that he could see out: ***"Dis nog lig en daars nog mense buite"*** for me reinforced my beliefs about a barren existence.

Jon, in giving his biographical details, explained the pressures to become a gangster: ***"Niks, niks om te doen nie, niks geld nie, niks nie en net heeldag in die huis gaan sit. En wanneer jy moet uitkom, as jy nie 'n bende behoort nie, dan druk hulle jou af en so moet jy hulle join".***

He admitted to feelings of dissatisfaction with his life: ***"Dis nie 'n toekoms in dit nie. 'n Mens geniet 'n mens se lewe, maar jy kan jou lewe nie geniet nie as jy elke dag moet omkyk, omkyk."*** He had just begun to leave the life of gangsterism behind to work as a bus driver, when he was shot, sustaining a C6 complete SCI. He had a Std 7 level of education. Jon described himself as taking an active father role prior to his injury especially with regards to his son who lived nearby. He maintains close contact with his children and sees them regularly when he is living in Elsiesriver.

3.4.2 **Ronald**, aged 30 years, lives with his wife, two sons and his stepdaughter in a two-bed-roomed semi-detached house in Mitchells Plain. He sustained a C5/6 sensory incomplete cervical spinal cord lesion three years prior to the interviews in a motor vehicle accident. He was the driver.

Each time the researcher visited Ronald, he was lying in bed under a warm duvet. His bedroom was a long narrow room with two single beds at opposite ends of the room, a wardrobe and a low cupboard on which stood a television and a portable radio. The window was boarded up (no money for repair?), giving the room a dark gloomy feel to it. His bed was positioned in such a way that when lying on his right side, he was able to

look down the passage to the small living area. Next to his bed was a chair on which I sat.

Ronald's wife does not work. His step-daughter was at home sitting in the yard at the gate and his wife seemed to be moving between the small kitchen and outside doing household chores. On the first occasion, the two younger children, aged 9 and 6 years, were also at home. They had overslept and so not gone to school. On my second visit they came in from school about halfway through the interview. They moved in and out the bedroom and towards the end of both sessions, came in to climb on their father's bed. They seemed attached to him, a fact that was very important and emphasised by Ronald throughout the interviews. Ronald described himself as a family man who took his family responsibilities very seriously. He was working as a security guard and studying towards his Std 10 at the time of the accident. He described how everything had seemed to be falling into place prior to his accident. He felt he had been progressing at work, had been doing reasonably well in his studies and had plans to study further once he had completed his Std 10. He had recently acquired the house and a second hand car for the family. He described himself as a hard worker who kept to himself and who just enjoyed being with his family, doing a bit of gardening after work and playing his sport.

3.4.3 **Willem**, the youngest of the three participants, is 19 years old. He lives with his older brother and his parents. At the time of the interviews, only his mother was working. Both his father and his 23 year old brother, had been retrenched. Willem lives in a small two-bed-roomed semi-detached house in Bonteheuwel on one of the main streets in the suburb. The overwhelming thing that struck me on entering his home, was how small and crowded the rooms were, a fact that Willem corroborated. He told me that he had never been into the kitchen, bathroom or parents' bedroom since his return home from the in-

patient rehabilitation centre two years previously. He shares a bedroom with his brother and a cousin.

Willem sustained a C5 sensory incomplete SCI in a shooting accident. He has not worked since his injury. Prior to that he had worked as a factory machine operator after leaving school with a Std 6 education.

I interviewed him sitting in his wheelchair in the small living room. The interviews were interrupted by noise from the street, and people knocking on the door. The family appeared to be a close-knit one, testified to by Willem in his interviews. The family appeared also to actively strategise to overcome obstacles and to make a plan for the benefit of the whole family with the greatest imperative being socio-economic stability. Who was working, who not, what income was coming into the family at any time impacted on plans for Willem, thereby creating uncertainty and no stability for him.

3.4.4 Key informant, **Igsaan,** is introduced very briefly. He sustained a C5/6 level SCI approximately 15 years ago as a 16 year old schoolboy. He completed his schooling at a special school, before going on to university to study for an arts degree. He is currently employed as a school counsellor. He continues to live with his parents in Mitchells Plain. His mother continues to be his primary caregiver in the home, but he has a paid driver and a vehicle of his own. The house, although small, has been altered to improve accessibility. He attributes his current situation to having a life goal towards which he has unswervedly worked, that of education and work, so that he could purchase appropriate equipment to compensate for his incapacity, have freedom of choice and control in his life and contribute to his family and society. He attributes his success to the support of his family.

## 3.5 DATA COLLECTION

### 3.5.1 **Method**

The informants were interviewed by the researcher in their own homes situated on the Cape Flats. Two in-depth interviews, lasting between forty five minutes and one hour, were held with each informant, with a time lapse of two to three weeks between interviews, to allow time for transcription and initial analysis.

Initial analysis of the interviews of the first two informants had been completed prior to the third informant's interviews. After analysis and reflection, a third member check interview was held with each informant to provide opportunity to add anything to the data and to improve trustworthiness of the interpretations and emerging categories.

At the first appointment, the purpose and methodology of the study was outlined in more detail and opportunity given for questions. Each informant was requested to read a letter of consent (see Appendix 3) and 'sign' it in whatever way possible. Informants were reassured that they could refrain from answering questions and withdraw at any stage from the study if they so wished. Permission for audiotaping of the interviews was requested.

In-depth interviews were the primary method of data collection. Interviews focussed on descriptions of their daily occupations and their experiences of these. By way of introduction, each informant was asked to describe a typical day for him. Purpose and personal meanings of their occupations they chose to talk about, were then explored in greater depth. In this way rich context description (Miles and Huberman, 1994), was sought. While the introduction to the research and the leading question at the first

interview were similar for each informant, subsequent content of the interviews was guided by the informants' subjective responses.

The first interview was introduced in the following manner:
"Occupations or activities are the ordinary familiar things that people do every day. I am interested in the ordinary everyday activities that you do, why and how you do them, and what they mean to you. Will you please tell me about a typical day for you now? What do you do? How is it for you?" Further probes explored roles, past interests and activities, future goals, resources enabling occupation, role of family and friends and feelings and perceptions around these.

The second interview was used to explore emerging themes after transcription and early analysis. The third interview was used for member checking of categories and themes that had emerged from comprehensive analysis of the interviews.

The interviews, held in the informants' own homes in an area decided on by them, were audiotaped.

Observations of the research informants in their own homes during the interviews were recorded in a journal. I had planned to use video sound recordings, but on arrival in the homes of the participants, I felt that this was unacceptably intrusive. Limited space in the informants' homes also would not easily allow for use of this medium for data gathering.

A journal was kept, recording personal thoughts related to my experiences and impressions in the informants' homes during the data collection, my personal reflections as I collected data and engaged in analysis, and my methodological concerns.

A key informant, Igsaan, himself tetraplegic, was also interviewed by me to improve trustworthiness of my understandings and insights gained in the data analysis prior to finalisation of the findings. Where appropriate, data generated by him has been used in the analysis.

### 3.5.2 Challenge of data collection

In order to gauge the quality of the data collected I feel it is necessary to present some of the insights that I gained on reflection of the interview process.

I approached the interviews with the basic assumption of all qualitative researchers, that informants are meaning-making and are able to talk from their own perspective. Hollway and Jefferson (2000: 27) highlighted for me the notion of "defended subject", a concept to which I had not previously been introduced. Some of the difficulties that I encountered in the interviews were clarified for me and are of importance to the audit trail as a method of repeatability. Hollway and Jefferson (ibid) suggested that a "defended subject"

- may not hear the question through the same meaning frame as that of the interviewer or other informants;
- are invested in particular positions in discourses to protect vulnerable aspects of self;
- may not know why they experience or feel in the way that they do;
- are motivated, largely unconsciously, to disguise the meaning of at least some of their feelings and actions.

This suggested to me that I needed to be vigorous in my analysis, and could not take what had been said at face value, resulting in an even greater reflexivity in the data analysis.

I used in-depth interview, with the expectation that the informant would lead the agenda once this was established through the introduction to the focus of the research and the opening question by me. I wanted the interview agenda to be open to development and change. I needed to consider that each of the informants, in trying to understand and comply with what they perceived to be my agenda, that their own stories may have been suppressed. The informants were not accustomed to being asked to talk about themselves, their experiences and their meaning these had for them. Data on the nature of their occupations was more forthcoming than the meaning and purpose of those occupations.

## 3.6 DATA MANAGEMENT

3.6.1 The first audiotaped interviews were transcribed verbatim and subjected to early analysis in preparation for the subsequent interviews. They were reflected on and used to formulate and reformulate questions, and to start grouping information into meaningful categories and themes, and to explore the researcher's personal biases, perceptions and opinions. The second interviews for each informant were also transcribed verbatim and subjected to detailed content and thematic analysis. The member check interviews were recorded only, not transcribed, as was the interview with the key informant.

The transcripts were made available to the informants on request, but none availed themselves of the opportunity. However in subsequent interviews, a summary of the previous interview was discussed with each informant with an overview of the researcher's understanding for verification of the data.

3.6.2 A computer software package, QSR NUD*IST VIVO (1999), Qualitative Solutions and Research Pty. Ltd. Melbourne, Australia, was used for early data management. The programme will hereafter be referred to as NVIVO.

## 3.7 DATA ANALYSIS

Data analysis proceeded through the following steps: (These cannot be readily separated, and should be viewed as overlapping and not necessarily sequential.

- Journal notes were kept after each interview of my impressions, feelings and observations which I felt might contribute later in the data analysis.
- I began with analysis as soon as the interviews had been transcribed and by listening to the audiotapes in order to plan for subsequent interviews. I aimed here to become immersed in the data and to become more fully aware of the life-world of the informants (Burnard, 1991). An interpretative framework was not imposed on the data. Rather I looked for it to emerge from the information that I obtained from the informants (DePoy and Gitlin, 1994). In reading through the transcripts one by one and by listening to the audiotapes, I made notes on general themes. Then re-reading the transcripts and doing a thorough content analysis of specific units of meaning relating to the research question, that is, the nature, purpose and meaning of occupation, was done. Meaning units in the transcripts were highlighted using the coding bar on the NVIVO progamme. Meaning units were named according to the emerging meaning. Similar meaning units or extracts from the transcripts were grouped together into open and tree nodes. This was the beginning of the developing category system.
- A co-coder, a professional colleague, well briefed in the research question, followed the same process without access to the computer programme. Comparison of

emerging themes and categories was made to enhance validity of the process. Unfortunately this could not be repeated, as the co-coder was not available in the later analysis stage of the study.

- Further analysis of the meaning units (quotes) in the NVIVO tree and open nodes, led to grouping and regrouping of categories. Some similar categories were collapsed into broader categories and some already broad categories were further analysed to create more categories. Relationships, patterns and themes between the sub-categories and categories were reflexively explored through repeated examination of the transcripts and the developing category system.
- The final category system, together with supporting extracts from the transcripts, was then presented to the key informant and to the informants themselves, to check the validity of the category system and the emerging themes. I presented the categories and themes to each informant and discussed the findings in a 40 – 60 minute member check interview, prior to the writing up of the final report. Only very slight modifications were made.
- A journal was kept throughout the analysis process to record some of my internal dialogue and to enable me to plan future analysis.
- In the writing up stage, carefully selected quotes were used to illustrate and highlight each aspect of the interpretation. Every attempt was made to remain true to the voice that was being quoted and the context in which the narration occurred.
- Extensive reading around the research topic further informed analysis.

## 3.8 TRUSTWORTHINESS

The concept of trustworthiness as developed by Lincoln and Guba (1986) was used. Trustworthiness was seen to include credibility, transferability, dependability, and confirmability. I have listed only those methods that I have used.

### 3.8.1 Credibility:

The goal was to increase the possibilities that the research produced credible results.

- Prolonged engagement with the data:

Leininger in Krefting (1991) suggested that credibility requires adequate submersion in the research setting to enable recurrent patterns and themes to be identified. Thus an important strategy is to spend an extended period of time with informants. As rapport increases, informants may give different and often more sensitive information than they do at first meeting. Application was limited due to the time factor. However, three interviews overall were held with each informant and it was felt at the end that no new data was being produced.

- Triangulation:

Cross-checking of the data was attempted (Lincoln and Guba, 1986) using a co-coder in the analysis, member check with a key informant and credibility of themes in the literature – both popular press and professional.

- Reflexivity:

With the realisation that it was not possible to separate myself entirely from my preconceived ideas about occupation and my own experiences in working with patients from similar backgrounds as the informants, I set about identifying my own assumptions, biases and beliefs about occupation, disability and living in poor socio-economic conditions. I acknowledged and attempted, by means of a journal, to identify my own pre-conceptions, biases and beliefs in the context of the research. My thoughts, feelings and ideas resulting from contact with the informants and with the raw data, were also

recorded and reflected on. As a researcher, it was necessary that I examine my subjective involvement because this could influences both the way in which I collected the data and the way in which I analysed it. Berg and Smith (1985: 31) advocated that "scrutiny is an absolutely necessary part of social science research" and that the process of self-scrutiny is central to our definition of clinical research because it can "yield information about the intellectual and emotional factors that inevitably influence the researcher's involvement and activity, and at the same time provide information about the dynamics of the individual or social system being studied". This process is also called bracketing (Brink, 1996).

- Peer debriefing:

This involved the researcher discussing the research process and findings with an impartial colleague who had had experience with qualitative methods. Insights were discussed and problems presented as a form of debriefing, as suggested by Krefting (1991). A co-coder in the form of a professional colleague was used to check emerging categories and themes as proposed by Lincoln and Guba (1986). Unfortunately she was not available in the later stages of research. Thereafter the emerging categories and themes were presented to professional colleagues in a research interest group, to elicit discussion and stimulate my reflexive discourse.

- Member checks:

The process of continuous informal testing of information by soliciting reactions of the informants to the researcher's reconstruction of what had transpired in the first in-depth interviews was done during the second interview. Krefting (1991) suggested that credibility could be enhanced in the interviewing process, through the re-framing of questions, or expansion of questions on different occasions. An attempt was made to do

this as a form of member checking. A third interview with each informant was held after analysis had been completed to verify findings.

### 3.8.2 Transferability:

- Thick description:

Lincoln and Guba (1986) described thick descriptive data as being narrative developed about the context so that judgements about the degree of fit or similarity might be made by others who might wish to apply all or part of the findings elsewhere. In this study the findings have been written up in detail with supporting evidence of informants' quotes from the interviews. Also description of the informants in their contexts has been reported.

### 3.8.3 Dependability and Confirmability

- Audit trail:

Audit strategy has been cited by Lincoln and Guba (in Krefting, 1991) as being the major technique for establishing both dependability and confirmability. To establish dependability, the audit trail focuses on the process, and to establish confirmability the focus is on the data, findings, reconstruction and interpretations. An external auditor attempts to follow through the steps or progression of events in a study to try and understand how decisions are made. Auditability also suggests that another researcher (peer debriefer) would arrive at comparable conclusions given the same data and research context. To apply this principle, I made use of a co-coder in the early stages of the analysis to confirm the emerging categories and themes. Unfortunately she was not available to check the final list of categories as she left Cape Town. I then referred to a key informant to check the authenticity of the data and the conclusions. My journal

served to keep a very rough audit trail of the analysis process. NVIVO also recorded processes by date and number. Reflexivity and peer debriefing, as discussed already, are also important for confirmability.

## 3.9 ETHICAL CONSIDERATIONS

- Protect informants from harm and ensure informed consent:

While potential informants for this study were identified by health professionals with whom they had had contact at some stage during their rehabilitation, participation in the study was voluntary. Informants were informed of the aims, purpose and process (time commitments, interview methodology, commitment to confidentiality) of the study. They were given opportunity to withdraw from the study at the time of introduction and at any stage after that. They were also given opportunity to read transcripts and feedback on emerging categories and themes prior to the finalisation of the report, although none availed themselves of the opportunity.

- Privacy and confidentiality

Permission for use of audiotaping was sought prior to each interview, and informants were free to reject it. The informants were reassured that they could stop at any stage they wished and that they had the right to decide what and how much they wished to reveal during the interviews. Every attempt possible was made to protect confidentiality and their anonymity in the course of the study and in the final report. No surnames were used at any stage and in the final report pseudonyms have been used. (The key informant gave permission for his name to be used.)

- Termination

A final meeting with each informant was held approximately a month prior to finalisation of the research report, to discuss findings and any issues that had been raised for them in the course of the study.

- Release of the findings:

The findings were made available to each informant for any changes they felt necessary, prior to submission, but none availed themselves of the opportunity. The findings were made known to them verbally. The results of this study should be made available to rehabilitation service providers. As it is wished that this study will positively influence rehabilitation services, it has been necessary to present the information in a way that will be positively viewed and valued by service providers. It is hoped that the final report will serve to sensitise occupational therapists and other rehabilitation professionals to the disability experience and its impact on occupation and vice versa. Knafl and Webster (1988) and Knafl and Howard (1984) highlight the importance of qualitative research studies such as this one to sensitise health professionals.

- Benefit to the informants:

The informants were informed at the outset that there would be no material benefits for their participation in this research. It could be conceived that opportunity to talk about and reflect on personal experience could be of indirect therapeutic benefit, or alternatively raise issues hitherto unfaced. The informants were informed of their freedom to withdraw from the interviews at any time. Situations mentioned during interviews which could be improved through intervention, for example an acute bladder infection, were met with concrete input on available resources at the end of the interview. Should this study sensitise professionals to the power of occupation in enriching the life experiences of people with severe impairment, the informants may experience a "secondary gain" from being in the qualitative study (Morse cited by Knafl and Webster, 1988: 217).

# Section 4

# FINDINGS

## 4.1 SUMMARY OF FINDINGS:

NATURE OF EVERYDAY OCCUPATIONS:

CORE THEME – ***"'n Boring lewe dié"***

| CODES | SUB-CATEGORIES | CATEGORIES | THEMES |
|---|---|---|---|
| Loss of active body<br>Loss of ability to move around<br>Can't do what I used to do (it's a struggle)<br>Lifestyle has changed | **Loss of active self** | LOSS OF THE DOING SELF | "KAN NIKS DOEN NIE":<br><br>FEELING TRAPPED |
| Can't work<br>Uncertain how to act/maintain relationships<br>Diminished husband role<br>Diminished father role<br>Loss of friends | **Diminished roles** | | |
| Loss of control<br>Dependency on others<br>Fear being a burden<br>Little choice in what I can do<br>Loss of freedom to do<br>Difficulty asking for help | **Can't do it on my own** | | |
| Lost dreams<br>Costs a lot<br>Shy of self | **Expectations limited** | **FEW OPTIONS** | |
| Health routines interrupt<br>Always in other people's time<br>Waiting for things to happen | **Time is not mine** | | |
| Feeling left out/left behind<br>Still shy of self<br>Can't get out/ world is shrinking<br>Planning is futile/barriers to doing | **Stuck in place** | | |
| Support to do<br>Family and friends enable<br>Doing through others | **Support for doing** | CONNECTED-NESS | STRUGGLING TO FIND A WAY |
| Being a father /being with his children<br>Being with friends | **Relationships are valued** | | |
| Doing feels different<br>Small things more visible<br>Watching, not doing | **Doing is different** | TENTATIVE MEANING - MAKING | |
| Have to pass the time<br>Doing for a challenge<br>Try to do what I did before<br>Visibility to get out<br>Talking takes place of doing<br>Looking for the positive<br>Acceptance to move forwards | **'Its better for me' :-little things to make meaning** | | |

## 4.2 Backdrop: Nature of occupations

On being invited to talk about their experience of what they now did each day, the informants described most often watching television, listening to the radio, 'just thinking', talking with family and friends, watching people and nature in their neighbourhoods, dreaming and sleeping. The limited repertoire of occupations in their daily routines, with the apparent lack of options, was harshly underlined by Jon:

> ***As dit reën en ek sit ... en die son skyn nie dan lê ek heeldag hier in die bed. Ek sal net I en TV kyk heeldag. Of ek slaap heeltyd. So ek slaap heeldag. Ek sal ne ... as ek wakker skrik moet hulle my net weer draai, en dan is dit net weer slaap. Wat anders?***[1]

There seemed to be few activities to mark the passing of time within a day, there also seemed very little to differentiate one day from another over time.

**Sleeping** was mentioned by all the informants as a central "occupation" with its purpose to pass time and its meaning to allow oblivion or dreaming. It was also described as a response to lack of opportunity to engage in meaningful occupations, and a way of coping with the interminable waiting for someone to come to facilitate occupational engagement. The sleeping patterns of the informants tended to be similar. They went to sleep late at night after watching the late night movie on television, and slept till late next morning, being interrupted only for the essential routine care tasks imposed by the spinal cord injury. The passivity, for me, seems to be emphasised by the phrase of dependency '***when they turn me***'.

In terms of the occupational science view of occupation – that occupations are "'chunks of purposeful activity" (Carlson 1996:144) which are typically "self-initiated, goal directed, and socially sanctioned" (Yerxa, Clark, Frank, et al, 1990: 5) - it could be argued that sleeping does not constitute occupation. Sleeping does not, however, typically demand concentration or engender an awareness of what one is doing during its execution, nor does it represent observable, concrete, personally meaningful indicators of personality and lifestyle, all suggested by Carlson (ibid) to be key attributes of occupation. However, in this study, it is evident that sleeping is 'potentially filling a given unit of one's time to achieve one or more desired goals' (ibid). For the informants, the purpose of sleeping was to pass time and to avoid thinking about an untenable situation in which they found themselves.

**Day dreaming** also was named as a common occupation. Two of the informants, Jon and Ronald, described their dreams as wishful for a different life, more in line with their pre-injury life goals and lifestyle. Willem used the term to denote internal dialogue with himself about planning for future occupations. Dreaming, however, was not necessarily satisfying and while Jon used it to try to avoid the reality of a life with too little active occupation, it merely served in another sense to accentuate his losses as illustrated by him:

> ***Ek droom die meeste van die tyd in die dag dat ek loop nou en ek is nou ryk en ek het my eie huis. Sulke dinge dink ek, en dat my vriende kom visit.....Ek het vanoggend gesê ek moet nie daaraan beginne dink; ek moet my mind op iets anders sit.....Dis lank dat ek aan iets dink en kom nêrens aan nie.***[2]

Sleeping and daydreaming were both identified by Toch (1992) as retreat occupations to cope with the eventlessness of a daily routine filled with lack of activity and stimulation. He suggested that the alternative was to engage in frantic activity, but this may be an option denied to people with severe physical impairment whose customary occupations have not included a lot of mental or intellectual pursuits.

Solitary activities, including listening to the radio, reading and watching television, were only possible if someone else was available to ensure that the setting supported independent action. A remote control for the television had to be in reach. Jon could only access it with his tongue. Reading required a lap tray on the wheelchair, and then lost its pleasure because of the difficulty in turning pages.

Given the time taken and the level of assistance required for basic care routines, they were not spontaneously mentioned as occupations by the informants. This might possibly indicate that these occupations had little meaning for them in the absence of an autonomous 'doing', although their purpose is clear.

Other occupations that appeared to add meaning to living, but which were not engaged in on a regular daily basis, and which were dependent on available resources (such as transport, finance, manpower), included getting out with friends or family – going to the game shop, to the beach, to church, to the movies. Willem described vividly his passion for playing chess, an occupation that served to give expression to his competitive personality and his social self.

Time spent with their children, reading and helping them with schoolwork, was highly valued by the two fathers, Jon and Ronald. Being with their children or parenting as

occupation, was perceived by the fathers to be giving concrete expression to their most important reason for living.

## 4.3 Outline of emerging themes

Against this backdrop of an extremely limited repertoire of occupations, three themes emerged from the data analysis, namely: 'It's a boring life', 'feeling trapped' and 'struggling to find a way'.

### 4.3.1. Core Theme: *It's a boring life*

This core theme permeated the descriptions of a typical day. The informants gave expression to their on-going struggles: waiting for assistance to "do" what they wished to do and their frustrations and feelings at not being able to "do" because of their own impairments and contextual barriers to occupational engagement. Even as the informants described their tactics to promote some form of occupational engagement, the evidence emerged of a daily routine without much variation to punctuate the passing of time and days.

Jon put into words the overall quality of time use as experienced by the informants:

> ***Maar 'n 'boring' lewe dié. Dis rêrig 'boring'.***[3]

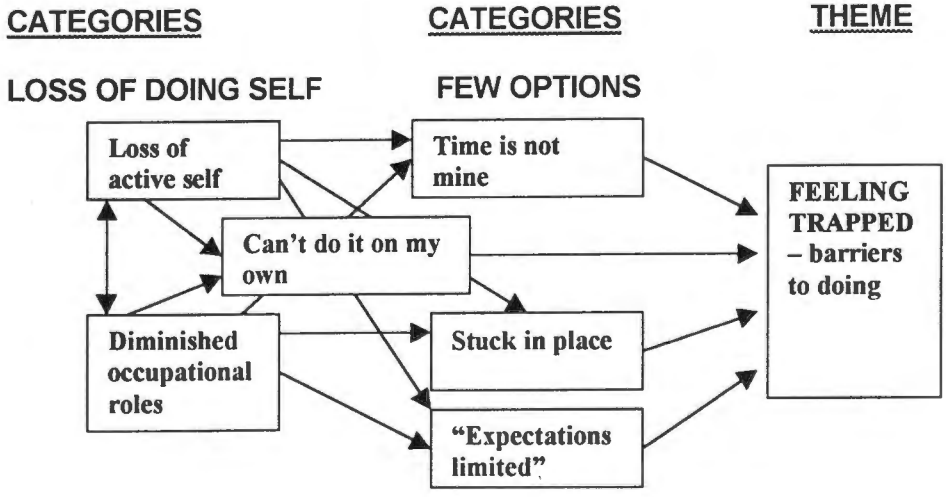
My observations of the informants in their own settings further confirmed for me that boredom was the central experience of a day with little to do, due to the severity of their impairment and also the limitations and restrictions in the environment.

Ronald, in the member check interview, suggested that the inability to do what he wanted to do, was the equivalent of a **"life sentence"** in prison. Their enforced passivity, the boredom resulting from the limited repertoire of activities and limited choice and autonomy certainly seemed comparable to the experiences of prison inmates described by Whiteford (1997) in her research on their occupations. This idea is also picked up in the discussion of the theme: 'Feeling trapped'.

## 4.3.2. Theme: Feeling trapped - *"Ek kan niks doen nie"*[4]

This theme emerged from feelings of being trapped, and of not having control of their destiny. Two of the men in this study, Jon and Ronald, seemed overwhelmed by their lack of variety and meaningful occupations and felt powerless to do anything to change the situation. Willem had ideas to increase his occupational repertoire. To some extent he had managed to take up a previously valued occupation by doing it differently, and felt less trapped as a result. The tactics used by the informants to try to increase their access to a more varied and satisfying occupational profile, are presented in the third theme.

The strong influence of macro and micro-environmental issues on the theme 'Feeling trapped' was evidenced by the categories illustrated below:



### 4.3.2.1 Loss of the doing self

The informants had lost their ability to engage in occupations in the ways they used to. As previously active individuals, in relative control of their destinies, they lamented that they could no longer competently act on their environments. The three sub-categories contributing to this category provided insight into the informants' loss of valued occupations and lifestyles.

#### 4.3.2.1.1 Loss of the active self (to engage in previously valued occupations)

'Doing' was equated with the physical act of doing something independently. It seemed that meaningful living was derived through physical activity for the three informants. The physical **loss of active body use** resulting from the spinal cord injury, symbolised the overall sense of loss experienced in everyday living devoid of a truly physical engagement in activities and occupations. Jon expressed his feelings of helplessness:

> ***Ek kan nou niks doen nie, dit is so, ek kan niks doen nie.*** [5]

By the use of the word "simple" (in the following quote, translated), Ronald shows how the loss of functional hand use had impacted on the most basic occupations by making them more difficult to accomplish, more time consuming, and therefore very frustrating to do:

> ***Hande is baie belangrik. Mense moet dinge met jou hande kan doen. Skryf, tik, deur 'n simpel boek te blaai. Om een bladsy vir my te blaai, vat vir my omtrent twee minute. Ek sal nou die hele boek so teen my maag druk of 'n***

> ***hoofstuk boek vat, blaai en blaas, blaas en blaai wat ek wil he en hoop ek kom by die blaai wat ek eintlik wil he. So sukkel ek met eenvoudig...die eenvoudigste ding.***[6]

The informants described their distress around the **loss of ability to do what they used to do,** that is the loss of previously highly valued occupations. Their self-identity seemed to have been largely defined by their propensity for 'doing' with the physical body. They all described themselves as having had an active involvement in sport and sporting activities at a formal and informal level. The loss of the occupation of sport had a profound impact, not only on their image of themselves as physically able sportsmen, but also on their social selves. Jon and Ronald had belonged to sport clubs, and Willem had engaged in sport at an informal level, playing soccer and cricket in the neighbourhood streets and skateboarding for hours at a time. Jon experienced his inability to engage in sport and roam the neighbourhood with his friends as an extreme loss. It had left a void in his life both in terms of time use and of socialising with friends.

> ***Ons was baie sportief en elke dag, elke dag wat 'n mens kry, sport gedoen en practise. Om nou so te sit is vir my swaar, want dis nou amper drie jaar. Ek sal nie kan aanpas, ek sal dit nie kan aanvaar dat ek so is. Ek weet nie hoe nie.***[7]

Willem highlighted how his **lifestyle had changed** by contrasting it with his previous lifestyle. He described himself as always being on the go, never having time 'to be' at home with his family.

***Weekends my family won't even see me at home. They will see me in the morning here. The evening they won't see me, because I will go out, come back the next morning and go to bed. Wake up the next morning later. I was a skater, a skateboarder. First, ja, I went to town, come back, go out again, come back tomorrow morning. Church was on Sunday morning. Go to church, come back, go to friends, come back, go to work the whole week..... ja, and I were playing sports, playing soccer, playing cricket, tennis. Whatever I can do, I will do. But now this has all changed and I have to get something else to do now.***

He added for emphasis:

***I can't do the things I used to do. So that means I can't go to the clubs where I used to. I can't skate anymore. I can't go to the movies. Ja, I, I can get into a car and go somewhere. I can maybe go to the beach, but that's not an everyday activity, so I must get something to do everyday for me.***

How this change in lifestyle had impacted on his occupations and use of time was clearly demonstrated by Willem as he contrasted his current state 'being' with his previous state of active 'doing'. His constant 'doing' had now changed to more 'being':

***At first everything is a rush. You, I will go out just. You come in from town, come in about now, just in and go. But now I have the time to think, think more about things, think what is going to happen tomorrow, what am I going to do tomorrow to get through the day.***

The **loss of ability to move around,** a consequence of the loss of the active physical self after spinal cord injury, here also referred to their loss of independent mobility and the difficulty in getting from one place to another. The environment contributed to lack of ability to move around. Living on a second floor of a block of council flats and limited space allowed little manoeuvrability or place for storage of equipment (so rather do without). There was a perceived lack of safety for the vulnerable defenceless person moving around in an area known for its gangs. These were some of the issues faced by the respondents living in their own communities. My own observations included lack of access to assistive devices such as light-weight wheelchairs and equipment to facilitate transfers. These added to the contextual issues that handicapped the informants. Transfers out of bed into the wheelchair required the assistance of two helpers for two of the informants and meant that they were bed-bound until help could be found.

Jon highlighted the impact of the inability to move around independently on his freedom to choose the time and place for his valued occupations:

> ***Hulle sal my altyd af help, maar, ek bedoel, jy kon rondgery het waar jy wil. Ek was nou drie jaar in die stoel en ek was nooit weer in die Kaap nie.*** [8]

#### 4.3.2.1.2 Diminished in relationships and occupational roles

A thread of **uncertainty how to act and how to maintain roles and relationships** ran through the interviews.

Jon, recognising the fragility of his relationships and the need to compromise his own behaviour in order to maintain them, bemoaned:

> ***En nou maak die stoel vir my so moedeloos, en jy is, hoe kan 'n mens sê, jy is so vir bad luck, nors en jy haal dit sommer op enige persoon uit wat hier is. En ek is bang dat ek my vriende gaan verloor as ek so maak, ja, as 'n mens so nors is. Jy weet nie hoe om die situasie te hanteer nie. Jy's sommer nors met enige een. So gaan jy jou vriende verloor.***[9]

The implication was that a person with disability, in order to maintain relationships, needs to work harder at them and make more compromises than someone without disability. It is perhaps reflective of their own pre-injury attitudes and beliefs about the worthiness of having friends. Jon talked about his inability to understand why his partner and previous friends were sticking by him, especially in light of the fact that he, prior to his injury, did not have time for them:

> ***En even my meisie wat ek nou het. Ek en sy het uitmekaar gegaan, oo so nege of agt jaar terug, en ek het vir my 'n ander meisie gehad. En dat ek so is, het die meisie my gelos en toe sy nou teruggekom na my toe. Ek kan dit nie verstaan hoekom sy nou hier is. Ek het al die tyd nie met haar gewoory nie, en nou is sy weer hier. ...Nee ek kan dit nie verstaan nie.... Ek, ek het nie tyd vir haar gehad nie, en, ek bedoel, dis nie enige mens wat so sal terugkom na so 'n persoon. Want kyk, ek is nou in 'n rystoel, en dis nie dat ek nou normaal is nie, dat sy terugkom. Want ek is in 'n rolstoel.***[10]

The loss of the ability to physically express feelings was described as a loss and as impacting on their **roles as fathers**. The inability to move independently around the house and neighbourhood meant a dependency on their children having to always come to them, in contrast to their being able to go to their children and 'do' things with and for

them. This increased feelings of anxiety around their abilities to be good fathers. They felt vulnerable and uncertain about their relationships with their children and felt it necessary to make personal compromises in order to maintain these highly valued relationships. Ronald described how his lack of physical capacity stopped him from taking an active role in the disciplining of his children and how he felt that they sometimes took advantage of him:

> ***Um, my ratings (as Father), as ek die engelse term kan gebruik, het so kleine bietjie gedaal.....As hulle nie, wil nie totaal alles doen wat ek nou van hulle vra om wat ek wil hê, hul agter my rug sal daar altyd 'n stoutigheid aangaan soos wat ek, wat die, wat die kinders betref, ag maar soos elke kind maar stout is as die pa en ma nie dophou nie, sal hulle altyd verkeerde dinge aanvang en so aan. Dit is nou buite my bereik en ek kan ongelukkig nie iets daaromtrent doen nie. Dis iets groot vir my.....Ek voel somtyds hulpeloos, ja, as ek hulle nie kan bykom as ek vir hulle so 'n so 'n twee gee of 'n blikkie on die oor in.***[11]

He particularly valued himself as the head of the household, an identity which he was now finding difficult to maintain from his bed where he seemed to spend much of his time. He described how he was willing to make compromises to keep his children coming to him, even when he didn't feel like spending time with them. He recognised that they gave him company and that being with them brought him pleasure and enjoyment.

> ***Nou dinge het baie verander. Ek het nou gewoond, soos u kan sien, ek het nou min tyd met hulle, en hulle sien daar is 'n verandering. Pa het nie baie tyd nie. Hulle kom gesels en lê op die kooi. Sommige keer as hulle so op***

> ***my spring, amper asof ek 'n jumping castle is, maar, um, ek kannie anderste nie.....ek moet hulle tevrede stel elke hoek en hulle nie weg wys nie.***[12]

Jon poignantly described his feelings around his inability to hug his daughter when she came to visit him and his envy when he had to watch his friends playing with her.

> ***En partykeer speel hulle en as my vriende hier is en hulle speel met my vriende, dan voel ek so jammer dat ek so is. Daai is my job en ek moes hulle pa gewees het en met hulle speel. Dan raak ek jaloers partykeer. Dis nie lekker as jy sien iemand anders speel met jou dogter. Jy wil dit nou ook doen, maar jy kan dit nie nou doen nie.***[13]

The feelings of uncertainty and inadequacy accentuated by the absence of physical ability to cuddle, play with, discipline and control their children were echoed by both fathers. Not being able to physically "do" with their children, left the men with feelings of inadequacy to fill their previous roles. Their perceived personal and social identities as fathers were threatened. This contrasted vividly with their pleasure at 'being' with their children, even in the absence of being able to 'do' in the same way as before the injury. The implication was that dependency on their children for even the most mundane of activities had diminished them as human beings in the eyes of their children.

Ronald similarly described his fear of losing his wife because of his feelings of inadequacy as a sexual partner. Again the loss of physicality which so defined his everyday living before his injury, was threatening his identity as husband and his very existence.

***Wel, Mevrou, solank ek my vrou kan tevrede stel, is dit vir my 'n troosding..... Dan weet ek daar sal nie nou 'n ou intussen inkom, mmm, en probeer inmeng of so nie. Dit is nog 'n moontlikheid. Maar ek probeer om nooit jaloers te wees nie want dit sal niks help nie.***[14]

**Loss of old friends** was a theme that was repeatedly echoed by the three men. Jon spoke of new friends, people that he had known before his accident, but with whom he had not really previously mixed. The insinuation was that they had not been the 'in-crowd', and not worth worrying about. Now the option of choosing friends was no longer his, as he was unable to engage in the occupations that they did. In his state of dependency he considered himself unworthy of their friendship.

***Maar die vriende wat ek gehad het, is nie nou my vriende nie. Dis nou ander vriende wat ek het. Die vriende waaroor ek nie much geworry het, hulle is die wat nou hier kom.....Nee, hulle was vriende van my, maar ek was nie close met hulle as wat ek met die ander gewees het nie. Ek is verbaas om te sien dat hulle kom hier na my.***[15]

These feelings of inadequacy and unworthiness in his present impaired state, were a reflection of his own pre-injury attitudes and beliefs about people with disabilities. His uncertainty how to act around his former friends, caused him to avoid them and served to reduce his mobility outside his home environment even further than the imposed physical restrictions.

***Ek voel nie eers meer om daar wil buite stap nie. Ek stap net in die pad af. Ek sal net tot hier by die hoek gaan en dan kom ek terug, want ek voel nie***

***om daar te gaan nie. Ek sal liewerste by die game shop by my ander vriende daar agter, maar, ding is, ek meng nie met almal hier nie. Ou vriende van my wat ek nie much wil sien nie, want hulle, as hulle by my kom, dan stap hulle verby. So ek, ek ignore hulle maar. Dan stap ek maar altyd in 'n ander rigting in wat ek weet ek sal nie vir hulle nog sien of so nie.....Dis beter vir my dan.....Dan avoid ek maar either vir hulle. Ek sal net sekere plekke gaan.***[16]

The loss of self-worth was expressed in terms of social interaction with the people around them.

Ronald felt his dependency and inevitable loss of control over his home and family keenly, as has been evident in some of the quotes already given. The loss of a productive **worker role** was particularly painful to him, as it highlighted for him the loss of an income necessary for the fulfilment of his dreams for a very different future for him and his family. His description of himself emphasised how much he had lost. He described some of his life goals prior to his injury – he had been studying, was in the process of acquiring his driver's licence, had acquired a family home and car, and had ambitions for promotion at work. He now expressed his future as ***"Expectations limited"*** This expectation served to subjectively limit his options to act on his environment and 'do' even further than the restrictions imposed by his impairment and activity restrictions. Ronald's passivity, as he lay in bed, waiting for his wife and children to come to him, to do for him, and his unwillingness to consider alternative ways of doing, was striking. He still fostered hope that he would work one day, but hidden in this was a dream that he would recover the use of his body so that he could proceed with his life in the way that he had planned.

> ***Ek, um, my droom wat ek graag hê, wat sal gebeur, is dat ek eendag my bene terug kry, weer selfstandig word, independent, my hande weer terug kry om iets te doen, en my kinders kan optel en cuddle en so aan. Dis vir my baie belangrik. En weer natuurlik my tuin in kan krap soos ek gewoonlik doen. Ek wil net dinge doen wat ek gewoonlik gedoen het. Dis al.***[17]

He finished describing his dreams and ambitions for himself and his family with:

> ***Dis al my drome, maar dis alles vir niet. Maar ek dink nog daaraan. Miskien kry ek nog eendag 'n gewone werkie.***[18]

Willem and Jon also mentioned their work prior to their injuries, but seemed less disturbed by their inability to work in the present. This could be attributed to the fact that both had only been working for relatively short periods prior to their injuries and had not yet absorbed worker/employee self identities. Willem described himself as an out-going athlete, lover of action and having fun with his friends. Jon's lifestyle, while very different from his former active lifestyle, might well have preserved some similarities to his period of unemployment. He described his lack of personal agency during that time, and his relative lack of occupational choice, as a result of the environment in which he lived. He saw himself as having no option but to join a gang in order to integrate into community living. However, not even this option was open to him now.

> ***Maar as jy nie werk het nie, om te bly in die ongewing, gaan jy aan die bende behoort want.....niks om te doen nie, niks geld nie, niks nie en net heeldag***

***in die huis gaan sit. En wanneer jy moet uitkom, as jy nie in 'n bende behoort nie, dan druk hulle jou af en so jy moet hulle join.***[19]

#### 4.3.2.1.3 Can't do it on my own

The experience of **dependency on others** in everyday tasks was described eloquently by the informants. Uppermost was their **fear of being a burden** to their families and friends. They expressed their unhappiness at having to always depend on others for every little task and activity during the day, from getting something to drink, to having a bath, to having to be lifted from the bed to the wheelchair. Ronald said:

***Wel, dit is 'n, dit is iets wat ek nie kan, dit is iets wat ek nie kan eintlik, iets wat ek moet aanvaar as 'n gestremde. Ek moet mense, enige mense se hulp aanvaar.....Dit is maar swaar, ja, dis reg. Ek moet nou unfortunately my trots in my sak druk en nou maar vra vir 'n sakdoek om my neus te snuit of krap aan my kop wat juk, of my rug wat juk, of my sak leeg te maak want dis nou tyd. Ja, of vra " bring gou water vir my."***[20]

It seemed that acceptance of a new identity as a disabled person remained tentative and that he remained uncomfortable with it.

Limited access to resources that could reduce the caregiver burden was highlighted by Jon:

***Dit sal vir my makliker gewees het en dit sal vir my meisie makliker gewees het as sy nie my orals sukkel op die stoel te sit nie. Sy moet elke keer wag***

> ***vir iemand anders om haar te help om my op die stoel te sit en my te draai. Ek kon dinge vir myself gedoen het en nie so afhanklik gevoel het soos ek nou voel nie. As ek nou wil uitgaan, sal ek myself kon stoot het, maar nou kan ek nie.***[21]

All three informants talked about their **difficulty in continually asking people for help**, although they all came to rely on significant people in their environments – their immediate families, including the children, appointed personal care attendants and special friends who saw them as more than just disabled.

That caution had to be exercised around how much one could ask for assistance and impose on friends was expressed by all three informants. Jon, in talking about his dependency on his friends to get out of the house and to go to the sport field, illustrated how consideration for others and fear of being a burden, limited access to favoured pastimes:

> ***Anderste sal ek baie daar wees, alhoewel ek nie kan speel nie. Maar as niemand jou kom haal nie, hoe kan jy daar kom? My vriende kan ek nie elke dag vra om vir my te kom haal nie.***[22]

In a similar vein, uncertainty around the ability of others not intimate with all their physical needs, to be able to deal with problems, also served to reduce opportunity to get out of the house.

***I'm still feeling that a bit, a bit, I can't ask this friend for this because he don't know what to do. So I'd like rather ask all my other friends. There's still that feeling, but I guess I'll get over it sometime.***

Sometimes things were not done to satisfaction, but there was a reluctance to object or take control of how or when care routines took place, because of the reliance on other people to 'do' for them even the most basic tasks and activities. Lack of choice in how something needs to be done, was reflected on by Ronald:

***Mens raak sommer dat jy frustreerd as 'n ding nie gedoen gekry soos jy dit wil he nie, (maar) 'n mens raak gewoond daars nie 'n ander alternatief nie.***[23]

He gave the example, which also serves to illustrate another sub-category – '**always in other people's time**':

***As 'n mens so lank...op die oomblik lê ek lekker snoesig in my duvet in en my, nog 'n tweede – wat is die ding waarop ek lê? – kombers. Soos ek nou 15 minute so kaal moet lê voor iemand my aantrek, dan irriteer dit vir my.***[24]

In contrast to the tentative meaning-making that is discussed in the last category, the loss of meaning in some previously highly valued tasks and occupations as a result of their dependency and loss of autonomy, was made evident by the informants. In familiar self-maintenance routines, Jon described how the act of eating had changed its meaning for him when he could no longer do it on his own.

> ***Ek kan nie eers vir my 'n koppie tee maak nie. Wanneer laas het ek 'n koppie tee gedrink? Want ek kan dit nie self vashou nie, en as iemand vir jou moet voer, dan is dit altyd 'n vinnige proses want jy wil nie hê die persoon moet lank staan hier by jou nie.....dan drink ek maar om gou klaar te kry en dis nie lekker nie.***[25]

Willem gave similar examples. He used to enjoy going into the kitchen to make snacks for himself, which he enjoyed eating. Eating was now a matter of survival. He had voluntarily eliminated breakfast from his daily routine to reduce caregiver burden.

Ronald described his daily ablutions as being modified to a "***cowboy splash***" done for necessity, and that the bath that he used to love as now being a major mission requiring at least two helpers to carry him and put him in the bath. His assurance that he enjoyed bathing, rang hollow against the background of:

> ***Wanneer dit rêrig nodig is vir 'n ordentlike bad, dan sal ek afgedra moet word tot by die bad wat alreeds vol is. Die water is al ingetap en dan 'n ordentlike bad hê soos 'n gewone mens.***[26]

He described the procedure in some detail, finishing off with

> ***Oh well, ek is al gewoond aan die prosedure.***[27]

This and his repeated use of the words "***soos 'n gewone mens***"[28] served to emphasise his feelings of not being human, of feeling diminished by his extreme dependency.

He suggested that, with time had come an acceptance of unpleasant routines. There was no alternative but to accept the situation. Still on the topic of basic care routines, Willem described how he had removed himself emotionally and cognitively from these, by engaging in casual conversation with his caregiver around unrelated topics while his physical needs were being attended to.

> ***I'm not really in the situation here. I'm still the same person. And I can talk to him and he can talk to me as human beings, as individuals.***

Jon described how hanging out with his friends no longer felt the same because of his dependency and his inability to participate on an equal level. He felt self-conscious about being different. Leisure activities for him had changed their meaning as their 'doing' had changed. He described his attempt at resuming the previously valued occupation of going to the soccer field, albeit as a spectator and not as a player. The experience emphasised for him his dependency.

> ***Maar dis nie eintlik vir my nog baie lekker op die veld nie, want almal hou jou so dop en amper soos, ja, okay, 'n mens is nou verlam, nou maar, hulle hou jou so dop asof jy nou van out of space afkom.***[29]

### 4.3.2.2 Few options in everyday living

The previous category **'Can't do it on my own'** also contributed to reducing options to engage in occupations in everyday life. The informants described how their dependency on others for the most basic occupations, their fear of being a burden to family and

caregivers and their difficulty in asking some people for help, impacted on their freedom and choices in everyday occupations.

#### 4.3.2.2.1 Expectations limited

This category emerged from codes of meaning which reflected the informants' limited expectations for a different kind of 'being' and 'doing' for themselves. It seemed to be induced by both personal beliefs and attitudes of the informants towards disability and the knowledge carved out of their life experience to date (both pre- and post-injury), as well as the attitudes and beliefs of the people around them. Ronald expressed this with:

> ***Verder kan ek nie veel verwag uit die lewe nie. In my kondisie is dit, ... mm, expectations limited.***[30]

Ronald was describing not only his loss of dreams for a different future for himself and his family, but also, I think, his limited expectation of a long life with quality. Underlying this statement was his threatened identity in the face of his loss of role as family provider (with its concomitant feelings of low self worth), and his fears for a meaningless future existence in the face of financial hardship and a very restricted range of daily activities. All these contributed to a boring existence – a core theme of this study. Sadly, he equated his existence with all its losses and restrictions, to a "***life sentence***" in prison.

Personal vulnerability from a health perspective, combined with significant contextual barriers to meaningful occupational engagement, would seem to be a recipe for loss of motivation and creativity. Jon expressed his vulnerability and loss of a future as an occupational being:

> ***..ek sal seker nie baie lank in die stoel sit nie, dan sal ek weer in die hospitaal lê. En as ek weer in die hospitaal lê, dan weet ek ek sal nie weer uitkom nie.....Baie keer voel ek in myself ek kan nie lank lewe nie, want mense in stoele lewe nie so lank nie.*** [31]

Absence of personal assistance and lack of other enabling resources such as finance was seen by Jon to contribute to his loss of personal autonomy and choices (as discussed in the previous category). It also accentuated how the perceived lack of available options to support daily living and limited opportunity or ability for occupational engagement, contributed to a day with a limited repertoire of occupations and very little variation in day to day routine to punctuate passing time:

> ***As ek die heeldag sit, so alleen in die huis sit, moet ek sê daar is niks anders wat ek kan doen nie.....niks, niks om te doen nie, niks geld nie, niks nie, en net heeldag in die huis gaan sit.*** [32]

Uncertainty existed around the permanence and reliability of personal assistance to fulfil basic self care tasks and other occupational routines. This left the informants with feelings of being unable to plan for occupational engagement. Not knowing when and how much assistance would be available, made future planning very difficult. Similarly worry about finance, health care and other daily living issues, took up time, but served to accentuate the loss of options available to these men.

***Daar is nie elke dag 'n persoon nie en die persoon wat na my kom kyk, het siek geraak nou kort, en sy's nou nie meer daar nie en ek weet nie wat ek gaan nou kom, wat voorlê.***[33]

Jon highlighted the precariousness of his existence and the futility of planning for any meaningful occupational engagement. He felt that very few options for a different existence were available to him in terms of creating an enabling environment. His dependency on family and friends was preferable to living in an institution, which would give him even fewer options than he had at present.

***Ja wat, as hulle nie daar is nie, waarnatoe gaan ek dan? Ek wil nie in 'n home gaan sit nie. Dis nie die moeite werd om daar te sit, want hulle kyk nie mooi na jou daar nie.***[34]

#### 4.3.2.2.2 Time is not mine

This category relates closely to the loss of control already discussed. The very nature of occupation implies purposeful and meaningful use of time. What seemed to be identified by the informants, was their lack of constructive and productive time use. ***Waiting*** for help to 'do', and always having to 'do' when it was convenient for the helper and at a rate determined by the helper, made planning for meaningful use of time very difficult.

***Well, I've learned that if I can't get it now, I must just wait. Or if it's not here, then its not here.***

This **waiting for help** was compounded by the sense that help was not always readily available nor provided in a consistent routine and was therefore not to be relied on.

> ***Elke dag moet jy net lê en wag vir iemand om na jou te kyk.....Ja dan wag ek vir my broer se dogter om my te kom help, maar sy kom ook nie elke dag daartoe nie. As sy kom, dan kom sy baie laat.***[35]

A further dimension of the illness experience that impacted on ability to initiate and persevere with meaningful occupational engagement was that of the necessity of following strict health routines for survival.

Jon described how he was unable to sit for long doing anything due to postural hypertension:

> ***Dan cut ek uit. Dan moet hulle my teen die kas tilt en dan is ek reg as ek vir 'n tydjie so sit. So vir 'n uur of so, dan is .....dan sal ek regkom.***[36]

Willem illustrated how the bowel routines interfered with his ability to participate in important family celebrations:

> ***.....like yesterday it was my Mommy's anniversary, and I wanted to be up. Okay, and I couldn't.***

Ronald, in describing the time that he spent with his children as being very meaningful to him, also implied that the care routines conflicted with time he was able to spend with them and what he was able to do with them. Because of the very limited space in the

bedroom and the position of his bed against the wall, he was unable to interact with his family when he was lying on his left side as part of his pressure care routine.

#### 4.3.2.2.3 Stuck in place

Being visited and visiting with friends were considered important in breaking the boring routine and the feeling of being **stuck in the house**. Being visited was not experienced in the same way as getting out to go visiting, but was the more common, due to transport and mobility problems of the informants. Contextual constraints imposed on the visitors, such as high travel costs and time for the visitors, also served to limit visiting. Ronald highlighted the prohibitive cost of travelling long distances as the reason for his old work friends not continuing to visit him. Jon highlighted the importance of being in a place where people could easily come to him (and especially his friends and children). His comparison of a typical day in an unfamiliar but more physically comfotable environment (Mitchells Plain) versus an environment where he was known (Elsiesriver), illustrated how important it was for him to be in an environment where he had a greater possibility of having company and physical support:

> ***Ek is nooit alleen in dié huis nie soos was ek in die Plain nie. Daar is altyd iemand wat hientoe kom.***[37]

While this extract seems to indicate that he had company all the time when he was in Elsiesriver, this was not so. He was contrasting the situations to make a point that some environments are more supportive than others. Out of his familiar environment in Elsiesriver, the quality of his day was perceived as being more boring and longer, with

nothing to break the deadly routine – no friends coming in, not able to get out without assistance and nowhere to go to – just **waiting** for his relatives to come home from work.

In addition to distance, travel and time costs, physical barriers in the environment and lack of transport served to make getting out of their homes more difficult and served to restrict their movements to and around their immediate neighbourhoods. Jon described that to get out of the tiny second storey council flat, he had to muster up help by shouting out the window for assistance to be carried down the narrow spiral staircase. Nevertheless he was adamant that this was preferable to being in Mitchells Plain where he had accessibility but no friends.

> ***In Mitchell's Plain is dit net ek sit daar, of ek gaan sit net buite in die son. Daar is niemand na my toe nie. Dis net my auntie en my uncle. Sien dis, daai is heeldag se ding elke dag, en dit is boring en ek raak vervelig so.***[38]

The lack of transport and ability to move around independently had resulted in the feeling that the ***world is shrinking***. That shut-in feeling and doing little of perceived value was poignantly expressed in:

> ***Die space is nou so klein. Jy kan nêrens gaan nie, maar net hierdie areatjie waar jy moet gaan.***[39]

The wider implication was the narrowed life focus and reduced options for occupational engagement. The difficult logistics in accessing assistance and transport simultaneously took away the freedom of action, of 'doing' on the spur of the moment. Jon illustrated this when he described how restricted his movements had become:

***Ek was nou drie jaar in die stoel, en ek was nooit weer in die Kaap nie.***[40]

He described one attempt to get someone to take him into the city, and how the outing at the last minute had been thwarted by poor weather. His disappointment and demoralisation, combined with a fear of being a burden, had prevented him from trying again. (In fact, at the final interview some months later, the only point of animation that he displayed in the interview, was when he described a visit into the city with his brother, a highlight for him in his monotonous existence and which he planned to repeat.)

An inability to access a wider range of relationships because of lack of ability to move around independently and the resulting dependency on 'waiting' for people to 'come' to them - themes of meaning echoed throughout the interviews, had left them with feelings of being left behind by life.

***Almal is besig en daar's min mense wat eintlik tyd het vir iemand wat in 'n rystoel is.***[41]

At a more esoteric level, being stuck in place (and time) was seemingly caused by a lack of acceptance of disability and unrealistic dreams for a better and very different future.

***Ek droom die meeste van die tyd in die dag dat ek loop nou en ek is nou ryk en ek het my eie huis. Sulke dinge dink ek, en dat my vriende kom visit.***[42]

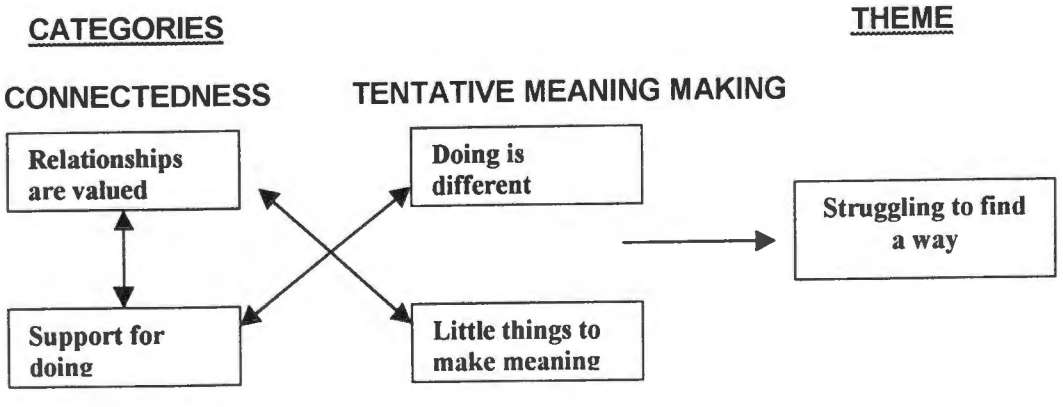
Jon recognised that his dreams had no possibility of fulfilment and were not helping him move forward, and he planned to change his occupation of dreaming with its purpose of

passing time, to 'do' something more productive. Ronald described how he continued to hope for a cure and implied an unwillingness to resume previous valued occupations such as studying, if these had to be done in a different way.

> ***Dit was altyd in die pyplyn om nog verder die vier vakke te doen om my matriek te behaal, en dan verder, dan verder vir my opgewerk het.....weens omstandighede, sal ek dit nie kan doen nie.***[43]

### 4.3.3 Theme: Struggling to find a way

This theme emerged from the categories **'being supported'** and **'tentative meaning making'** through occupational behaviours. The previous theme of feeling trapped served to emphasise the barriers to occupational engagement that the informants faced in their daily living. This theme counterbalanced the demoralisation and hopelessness around the difficulties of occupational engagement. I learnt something of the ploys used by the informants to enable more meaningful participation in previous occupations, albeit in a modified way. The informants, in different and individual ways, tried to resume some valued occupations or created opportunity for meaningful occupational engagement, giving credence to the idea that man needs to make sense of his situation by promoting occupational engagement at whatever level to make existence more meaningful.



### 4.3.3.1 Connectedness

#### 4.3.3.1.1 Relationships are valued

Social engagement, whether with family or friends, was seen as vital by the informants to add some meaning to their lives. Being father and watching their children grow up were seen by Jon and Ronald as providing meaning in their lives. Being able to interact with their children, even if only for a short time, added value to the day. Doing things with their children at whatever level was important to maintain connectedness within the family unit. Ronald described his role of teacher and storyteller to his children. He was prepared to endure the irritations as they used him as an object to climb on, so as to have them close to him. Jon used every ploy he could to get his children to visit him. His preference for living in the less accessible setting of Elsiesriver ensured he could use his 'knowledge, skills, and confidence to use the environment to carry out (his) own goals and to enrich his experience (Dunn, Brown and McGuigan, 1994: 596).

Ronald expended much thought and energy on keeping his wife satisfied within the marital relationship. This gave him an anchor in life.

Jon's insistence that he needed to live in the same neighbourhood where his friends were, showed how important this dimension of connectedness was for him. He saw his friends as the only potential to providing some meaning to his everyday living and considered it vitally important that he be in a situation where he could access them. He realised their potential for physically assisting him in tasks of daily living, and, more importantly, for the company and distraction they could provide for him through socializing. It was also through family members and close friends, that occupations, more

active and satisfying than watching television were enabled. Jon described this graphically:

> ***Hier's nou nie M-Net of 'n video of 'n colour TV nie, maar vir my is dit veel beter hier. Vriende is beter as TV, want TV kan nie met jou komuni – dinges terug praat nie. Maar vriende kan terug praat, ja, dis beter vir my ...ja.***[44]

#### 4.3.3.1.2 Support enables

Many examples have been cited how family and friends were valued for their assistance to the informants in carrying out maintenance self care routines and with accessing the environment. Family and friends added significantly to the meaning of existence, both because they provided occupation and because they enabled occupation.

Willem talked about he courage his family had given him to get out and 'do' again, when all he wanted was to stay in bed.

> ***Now we're at home, and there's something new for people outside, neighbours, people down the road. I couldn't face them at first, but....um, they (family) gave me courage to do that.***

Key informant, Igsaan, described how his family had also given him the courage to get out, mix with people and start living again. He felt this had helped him to redefine his life goals.

At a more practical level, Willem described how he was enabled by others doing the physical moves for him, when playing chess and snooker. He was able to demonstrate his mastery and control in a favourite occupation by having his partner be a physical extension of himself to do the moves dictated by him. As key informant, Igsaan corroborated this. He had discovered that people are very willing to assist him physically, and that once he had accepted people's right to say "no", it had become easier for him to ask for help. He admitted that asking for assistance had also become easier once he had created a relative interdependence in his household by being able to contribute in a specific way to the household – in his case with an additional income to contribute to the household living expenses. Willem seemed to be making tentative steps to create a reciprocal and equal relationship through his playing of chess. He felt able to compete on equal terms and better – he was also teaching the game to his brother and friends.

#### 4.3.3.2 Tentative meaning making

##### 4.3.3.2.1 Doing is different

One of the consequences of living with tetraplegia, was the change in the meaning dimension of everyday familiar occupations and routines, revealed on deeper examination of the data. Some examples are given.

- **Watching television gains in meaning**

Of the more traditionally considered passive pastimes, watching television was valued for more than just passing time. All three informants described how they valued watching television, mainly sport, with their friends and families, and how this provided a common point of contact in their relationships. The fellowship of doing something together, sharing

opinions and getting involved in something outside themselves, was the desired outcome. The two fathers saw television time, watching cartoons and movies and sport with their children as quality time. Television was a vehicle to share something and do something together with their children in the absence of being able to get out and physically do something with them. Willem described how he loved watching the news to keep informed about current events because this impacted on his relationships with his friends and personal attendant. Moreover it was congruent with his developing self-identity as a thoughtful young man. Television transported him into different lives and worlds. By immersing himself in the 'soapies', he was living vicariously through the experience of others. He was exposed to risk, challenge, uncertainty, all of which contributed to taking away the boredom of generally uneventful routines of everyday living.

- **Being with and talking to others**

The importance of being with others has been discussed under 4.3.3.1.1. Willem summed it up:

> ***Sit there and try and talk. Talk about what happened. Anything we can, not do but talk about ... just talk. I love to talk. I like to know about stuff going on around me.***

- **Chess becomes more than chess**

Willem used his love of chess to engage in social encounters with friends and family members. He felt he was able to do 'do' as well as before his injury. Adapted 'doing' made no difference in an essentially intellectual activity. The inability to physically move the chess pieces was a small price to pay for the feelings of competence and deep involvement he experienced as he played the game.

***The opponent who is playing against me, moves the pieces for me where I want and I'm quite good at it.***

The occupation of playing chess defined him as a human being with good mental ability, for which he felt respected by his community.

- **Watching takes place of doing**

Ronald described himself as an "***armchair spectator***". This served to highlight for me that 'watching' had been elevated to the status of occupation (such as watching sport on television, watching his children play) and that it was an active way of 'being' in the world. He described how he liked to position himself so that he could see more of what was going on:

***Buite, as ek buite in die wheelchaïr is, dan voel ek nou, ..ek voel nou sterker daar as in die koei. Ek het 'n breë seggenskap....omdat ek kan sien van alle hoeke af. Ek kan sien wie aankom, wie uitgaan.....***[45]

Similarly, each time I left Jon after an interview, he asked to be positioned at the window so that he could observe life in the neighbourhood.

Ronald described very vividly how he felt he had started noticing the small things in life and that he had become preoccupied at times with the contemplation of nature and the man-made environment. It had added a new dimension to his life.

> ***En dan is dit nou rêrig stil sit en diep dink, ... dan waardeer 'n mens al die klein dingetjies net so. Dan sien 'n mens hoe dit vanselfsprekend vat, die voëltjies wat verby kom sit, en 'n hond of 'n kind wat verbyloop, en jou stiptelik dophou, of selfs 'n vliegtuig wat verby vlieg en dan kyk jy dit so en wonder hoe kan hy in die lug bly, en allerhande goed. Dit raak 'n mens uiteindelik diep. So besef ek nou, ek het baie goed vanselfsprekend gevind soos die kwetter van die voëltjies, die groei van plante....en sulke dingetjies.***[46]

- ***Doing differently can be enjoyed***

Willem came to realise during his rehabilitation, that doing things could be done differently and continue to be meaningful. Already discussed were the adaptations used by him to enable his continuing satisfying participation in chess. He also described how, despite his own negative expectations, he had discovered enjoyment, creativity and control through mouth painting. He continued to feel excited by the potential of using his creativity, but on his return home, this occupation had been terminated due to inadequate financial and transport resources to support him continuing with classes or space to do it at home. Similarly he and Jon had been exposed to the potential of computers during their rehabilitation, but were now frustrated due to their lack of access to resources to support computer use as an occupation.

#### 4.3.3.2.2 Little things make meaning (Ploys to create meaning or cope with loss of meaning)

Informants, in the course of their interviews, illuminated several ploys they had adopted in an attempt to create opportunity for meaningful occupations or to cope with the loss of

meaning in other occupations. The refrain "***Dis beter vir my***"[47] or similar occurred throughout the interviews as as they described them. Some of the ploys have already been highlighted in previous discussion, as they are integral to the 'doing' of occupations, but will be listed here for the sake of completeness.

- **Something to 'do' to pass time**

Some kind of activity was verbalised as being important to help pass the time in a more constructive way than being stuck with nothing to do even if the activity no longer held the same meaning as previously, because of an inability to actively and physically participate. However the kind of 'doing' differed between the three informants. Ronald tended to remain in passive pastimes such as watching television, whereas Jon and Willem actively sought opportunities to get out and be with people outside the immediate family. Jon reiterated in the interview:

> ***Vir my is dit nie lekker op die sokkerveld te sit nie. Jy wil graag speel en jy kan nie. Jy moet maar net daar sit en dophou hoe die ander speel.....Dis al wat ek doen op die veld. Sit. Sit.***[48]

- **Getting out**

Jon realised that it was better for him to 'get out' with his friends and 'to pass time' in a more stimulating and less lonely way than if he had stayed at home.

> ***Dis net om uit te kom. Dis beter as wat ek in die huis so sit.....***
>
> ***Vat die tyd weg. Wanneer ek terugkom, is dit al weer aand, dan kan ek maar net kom was en slaap.***[49]

- **Variety in routine**

Ronald confirmed the importance of getting out and the importance for him to have different experiences to break up the eventless, boring day to day routine. He recognised that variety in daily occupations could add quality to life

> ***Ek vind dat hoe meer ek, hoe meer verskeidenheid aktiwiteite of mense ek sien, hoe helder dit 'n mens se lewe op.....dis nie so eentonig, jy sien, so boring.***[50]

The lack of variety and the relentless monotony of the daily routine were emphasised by him:

> ***Vir my is dit net my dinge as usual.***[51]

- **Visibility attracts company**

All three informants spoke about the importance of using strategies to make them more visible to their communities in order to let people know that they were still around. Yet they felt dissatisfied with the fleeting interpersonal contact that passers-by had with them and continued to feel left out of the mainstream of life.

> ***Almal is besig en daar is min mense wat eintlik tyd het vir iemand wat in 'n rystoel is. Hulle sal natuurlik net groet vir my. Hulle moet maar eintlik stil staan en vra hoe dit gaan en so aan, en redelik geselskap knoop met my, (maar) hulle sal net wink of groet en verbystap.*** [52]

- **Seeking continuity**

Returning to familiar territory and resuming previous valued occupations was seen as desirable, albeit not in the same way as before, for example, to participate as spectator at soccer rather than player. Difficulty was experienced accessing former occupations that could be pursued in adapted ways, due to lack of transport. For example, Willem felt he was unable to resume role of Sunday school teacher, or go the cinema. There was also a reluctance due to feelings of embarrassment and fear that something would happen:

***"Ek skaam vir my."***[53]

- **Opportunities for challenge and skills**

Willem recognised the importance of developing his remaining capacity for meaningful engagement in valued occupations - that of his mental abilities. He actively sought learning opportunities and competition to provide himself with challenge and to test his skills.

- **Future projects and a positive outlook on life**

Willem maintained that it was important to have a goal towards which to work. He spent time planning for future projects, but the struggle for him was the lack of personal and family financial resources, transport, community training facilities and space in his own home to achieve his personal goals. He maintained that it was essential to retain a positive and optimistic outlook on life.

Igsaan, as key informant, maintained that it was his personal vision that had helped him achieve the level of satisfaction through his occupations over the fifteen years after his

injury. His realisation that he had to further his education in order to achieve financial viability that could give him the lifestyle he wanted in spite of severe disability, had guided him past many apparent obstacles. Today he has achieved financial stability through employment in a satisfying job, and has developed an interdependence with his family and caregivers which does not erode his self esteem or leave him with overwhelming feelings of incompetence.

# Section 5

# REFLECTIONS ON THE FINDINGS

# SECTION 5: REFLECTIONS ON THE FINDINGS

## 5.1 Introduction

This study has confirmed for me that people with severe impairment who are living in lower socio-economic circumstances, do indeed have a very limited occupational profile (consisting in the main of predominantly passive type of activities). The extent of these limitations and the profound impact this has on how people live out their lives and make meaning of their existence, has been a revelation.

This discussion, based on my reflections of the findings and illuminated by the insights of the key informant, Igsaan, who himself is tetraplegic, and the literature, is an attempt to put into perspective the lived experience of an occupational being with severe impairment in relatively impoverished circumstances.

## 5.2 Framework: Doing, Being, and Becoming

A framework against which to reflect on and discuss the findings is provided by Wilcock (1998). She described occupation as the synthesis of doing, being, and becoming. She considered occupation to include "all things that people do, the relationship of what people do to who they are as human beings, and that through occupation they are in a constant state of becoming different" (ibid: 248). The informants described their state of 'being' as imbued with notions of 'doing' prior to their injuries. With their current absence of 'doing' as consequence of their impairment, so their 'being' or, in different phraseology, their self identity, is threatened. Reeve (1998: 272) confirmed this finding:

***As much as I remind myself that being is more important than doing, the quality of relationships is the key to happiness, I'm actually putting on a brave face. I do believe these things are true, but I miss freedom, spontaneity, action, and adventure more than I can say. Sometimes when we're up in Williamstown, I sit out on the deck looking across our pastures to Mount Greylock, and I remember how I used to be part of it.....I feel like a visitor at a spectacular outdoor museum.***

## 5.3 Becoming in the face of loss of Doing and too much Being:

In this study, the informants' lack of actively and physically 'doing' has possibly resulted in too much time for 'being', by them a previously undervalued state. The consequence has been feelings of boredom and entrapment, in the prison of their flawed bodies and an unsupportive physical environment. 'Becoming', with its future perspective of development and growth, does not seem probable in the absence of satisfactory 'doing' and 'being'. Ironically, with the lack of vision or hope for a better life, 'doing' and 'being' in the present time perspective is inhibited.

### 5.3.1 Loss of impact of self on the environment through occupations

#### 5.3.1.1 Occupational Termination

The informants of this study gave descriptive examples of a drastic change in lifestyle with their loss of valued occupations. As a result of their severe physical impairment, they were unable to continue with previously valued and meaningful occupations. Occupational termination, defined as "the phenomenon whereby participation in an

activity reduces or eliminates the possibility of subsequent participation" (Carlson, 1996: 153), was experienced as a sudden and extreme loss. The spinal cord injury resulted in severe incapacity, so that all physical 'doing' was rendered difficult or impossible. Reeve (1998: 271) had this to say about it:

> ***People often ask me what it it's like to have sustained a spinal cord injury and be confined to a wheelchair. Apart from all the medical complications, I would say the worst part of it is leaving the physical world - having had to make the transition from participant to observer long before I would have expected.***

While termination of the physically active pursuits such as soccer or skateboarding is obvious, it is less obvious why altered 'doing' may result in termination of an activity. A lower order activity such as self-feeding with an assistive device, was possible for all these men. Yet they often preferred to be fed, ostensibly because of the tediousness of the activity and lack of complete mastery. Insufficient care resources, a perception of the time / effort ratio for and perceived incompetence in this activity, resulted in partial termination. Additionally, the need to be sitting in a wheelchair to execute the activity was often not possible due to insufficient people to assist with transfer into the wheelchair.

Loss of vision for the future, a negative attitude towards the disabled self and perceptions of society's attitudes towards disabled people compounded the more obvious (and stated) difficulty in accessing costly resources to support the occupation and led to termination of valued occupations. For example, the occupation of part-time student, which at first glance seemed a feasible and reasonable occupation to pursue, given appropriate physical resources, was terminated by Ronald.

Occupations may be terminated for reasons other than physical incapacity as posed by the informants of this study. Previous experience in overcoming obstacles, acceptance of disability and the identity of self as a disabled person with different competencies, and the perceptions of the environment and its ability to support continued participation, were highlighted by this study. These findings are supported by factors promoting occupational termination as posed by Carlson (1996: 155), some of which are unpleasant experiences leading to negative future expectations, lack of resources necessary for participation, reduction in psychological fulfilment such as perceived mastery and boredom, and physical incapacity.

Occupational termination of valued occupations and roles by which a person has previously defined his or her self-identity and a life dominated by essentially passive occupations, has consequences for the individual. Activities and occupations valued only for their ability to support survival needs or for the ability to pass time, contributed little to feelings of competence and effectance in acting on the environment for these informants. This served to further accentuate their loss of doing.

There is "agreement that the single characteristic of an individual which has the greatest impact on occupational performance, is one's sense of competence" (Christiansen, 1991: 19). White (1971) defined competence as efficacy in meeting environmental demands. He theorised that the individual has an intrinsic drive to influence his or her environment and that it is this drive which motivates the individual to act. It is the successes achieved in transaction with the environment, that contribute to the development of a positive sense of self and feelings of autonomy and control, and which urge the individual to repeat an action or occupation. The contribution of the environment-behaviour theorists, such as

Bandura, Bronfenbrenner, Baker and Intagliata to the understanding of the link between occupational performance and the person-environment fit (Letts, Law, Rigby, et al, 1994), emphasised the transactional relationship between individuals and environments in enabling or disabling engagement in occupations. These theorists considered that the individual's experienced and personally perceived environments (social, cultural and economic), and their own perceived health status, were key to their willingness to actively engage in occupations. Physical incapacity combined with the inability to acknowledge potential affordances in the environment due to prior life experience may render that individual unwilling to even consider alternative ways of acting on his environment.

Inadequate capacity and inadequate environmental supports for the informants of this study did not support occupational engagement. Time and effort, perceived burden on caregivers, and previous experience of difficulty accessing physical resources, resulted in negative expectations of success. A consequence was the apparent resignation to a boring existence, and an emotional response of passivity and withdrawal by two of the informants. One informant (Willem) perceived himself as competent in some occupations, such as chess, and he appeared to have adopted a more agentic stance to occupational engagement observed in his active planning for future occupations: ("***I must find something for myself to do***") than had the other two informants.

The predominant passive pastimes, such as television viewing, do not impact the environment and are not achievement related, thus do not serve to enhance feelings of competence, and personal control, self esteem and well-being.

#### 5.3.1.2 Threatened identity

It is only through having an impact on the environment, that it is possible to measure self - a fundamental requirement in development and maintenance of self identity or 'being'. Self identity develops out of exploring, experimenting and 'doing' in the environment

Clark, Ennevor and Richardson (1996: 374) highlighted the assumption that "human beings constitute themselves through their occupations; they evolve as occupational beings and into who they shall become through their immersion in their daily practices, habits, and activities". They raised the same question that I did: "What happens if the obstacles to the continuance of being seem so great, that self construction cannot continue in the same way as before, as in someone who acquires severe impairment, and especially if that person lives in a seemingly hostile environment which does not support him or her as an occupational being?" (ibid: 374).

If, as already suggested, self identity is defined in terms of competence of 'doing', then, with termination of occupations and a repertoire of predominantly passive pastimes, self-identity would come to be defined in terms of failure and incompetence, with associated feelings of low self worth, loss of autonomy and control. Self-identity would be evident through a generally victimic stance.

The overwhelming emphasis in the interviews on the losses in terms of physical abilities and daily occupations and the relatively little attention to the positive experiences of daily occupations caused me to question further the concept of threatened identity.

Christiansen (1999: 547) maintained that self-identity is shaped in a social context by occupations which "*are key to not just being a person, but to being a particular person*". He considered that an understanding of self is based on the direct feelings and thoughts one has of oneself and one's ability to act as protagonist in one's life. Self esteem is related to ability to demonstrate efficacious actions and gain social approval. Self concept derives from the inferences one makes about oneself and is informed by the extent to which the perceived self (as competent or not) matches up to the ideal self. If previously valued occupations, by which one's identity was defined, are terminated, and the current limited range of primarily passive occupations do not provide the same definition of self, one's former or non-disabled identity is threatened.

A new identity which incorporates both the former self and the disabled self, can only develop from positive occupational experiences in which one has been able to impact the environment in some meaningful way. It follows that in the absence of meaningful occupations that inform a sense of competence and control, a negative self identity with low self esteem will develop. The self will continue to be defined only in terms of what one cannot do and the roles that one cannot fulfil.

Carpenter (1994) described this experiential split between the individual's concept of the external selves and internal selves following traumatic spinal injury. The external experience of disability or the physical changes resulting from the injury symbolised for the informants, the impairment and overall sense of loss. The radical change in body image and physical functioning were seen as separate from the internal concept of self, which was perceived by them as being unchanged and which represented their accumulated pre-morbid life history and experience. She felt that the accounts of the informants revealed the importance of regaining a coherent sense of self in which the

discrepancy between the internal self and their external self was resolved. She suggested that the final stage in establishing 'a new identity' was concerned with the roles that identify and describe the individual as a social being and that are central to a person's self concept. Identity as a whole was seen as the integration of both the inner and external experience of self' (ibid: 622). Implicit in the description of the findings in her study, was the role played by actual and potential occupational engagement over time.

The eventual merging of the internal and external concepts of self seemed to support to some degree the pendular model of reconstruction of self and identity posed by Yoshida (1993). She suggested that identity reconstruction is a process that swings like a pendulum between the disabled and non-disabled aspects of self. Between the outer positions of the pendulum representing the 'former self' and the 'disabled identity as total self" individuals may pass through and experience different degrees of the non disabled self and the disabled self, but culminating in what she described as the 'middle self' (ibid: 223). The following passage by Reeve (1998: 299) seemed to confirm this:

> ***Lately I have become to perceive my life as a continuum, rather than two parts divided by what happened on May 27, 1995. I'm thrilled when someone remembers something we shared at some point in my life. I believe this reaction means my mind and spirit refuse to let the injury define who I am.***

Implicit to both these studies is that the former or core self (prior to the spinal cord injury) is the basis of identity reconstruction, although the total self can never be recaptured. The core self is defined by previous life experience, by the attitudes and values towards

disability and the perceptions around the experience, and forms the basis for redefining a self identity after disablement.

### 5.3.2 Restricted autonomy and choice in occupations

While the person-environment transaction in the social sciences and in the field of rehabilitation (Hammell, 1995; Trieschmann, 1988; Law, 1991; Christiansen and Baum, 1997; Dunn, Brown and McGuigan, 1994; Letts, Law, Rigby et al, 1994) is not a new concept, the findings of this study have served to confirm that human experiences and behaviour cannot be properly understood if they are stripped of their everyday contexts (Jordaan and Jordaan, 1998). The context in which people with disabilities live their daily lives has a profound impact on what they do, how they do it, and what it means. Withdrawal and passivity in a person with disability is often labelled as lack of motivation by rehabilitation professionals. This study suggests that such a view is simplistic.

#### 5.3.2.1 Life Sentence

The core theme "It's a boring life" incorporated the informants' overall meaning experience of everyday living. There was little to break the monotony of a predominantly indoor existence, dominated by health routines and passive pastimes. The analogy "life sentence" used by Ronald to denote his feelings of being trapped in his own body, in his own home and in an untenable situation, was a powerful one.

The core theme 'boredom' suggested that the informants were living in conditions which excluded choice and opportunity for a variety of activities and occupations, that is they were occupationally deprived. Occupational deprivation is:

> ***A state of preclusion from engagement in occupations of necessity and/or meaning due to factors that stand outside the immediate control of the individual*** (Whiteford, 2000: 201).

While the primary causes of occupational deprivation (impairment, consequent occupational dysfunction and termination in a restrictive environment) for the informants were different to that of inmates undergoing prison confinement, the restrictions that were experienced by both resulted in occupational deprivation. The consequences of occupational deprivation were similar - sleeping, day-dreaming, boredom, apathy etc. The similarities to those found in studies on prison inmates (Toch, 1992; Whiteford, 1997; Molineux and Whiteford, 1999) are highlighted:

- Limited variation in daily routine to punctuate passing time and endless waiting (Whiteford, 1997).
- Eventlessness - includes retrospects of dreariness, feelings of boredom and future perspectives of redundancy and emptiness (Toch, 1992: 29).
- Reduced sensory and social stimuli (Toch, 1992) and reduced contact with people outside (Whiteford, 1997).
- Restricted use of tools and equipment (Whiteford, 1997).
- Inability to access wider environmentand deprivation of liberty (Molineux and Whiteford, 1999).
- Occupational role constriction (Molineux and Whiteford, 1999).
- Lack of meaningful time-use (Whiteford, 2000: 203). She lists it as an impact of occupational deprivation. I suggest that it is also a cause.
- Maladaptive response to occupational deprivation - sleep (Whiteford, 2000).

- Barrier to community re-integration due to atrophied occupational capacities, diminished self efficacy beliefs and truncated identity constructions (Whiteford, 2000).

Occupational deprivation over extended periods has been shown to have a detrimental effect on health and well-being of the individual.

#### 5.3.2.2 Specific contextual issues

The contextual issues which contributed to this feeling of entrapment, should be seen against the background understanding that the way in which we engage in the world and what we do, is largely dependent on environmental factors - both immediate and intimate and the broader milieu (cultural, economic, political and social) (Letts, Law, Rigby et al, 1994).

##### 5.3.2.2.1 Physical environment

Inaccessibility whether assistance was available or not, was problematic for the informants. Limited space in their homes precluded access to all the rooms in the house. The outside environment could only be accessed with assistance, due to physical barriers such as steps. It was also not conducive to easy access due to unsuitable terrain for wheelchair access.

Access to the wider neighbourhood was limited due to both perceived danger factors (violence, gangs, theft) and feelings of vulnerability, and by unresolved feelings and lack of acceptance of their impaired state: "***Ek voel nog skaam***"[54]. Toch (1992) highlighted how concern for physical safety led to a preference for social and physical settings that

provide protection. Thus being housebound was preferable to accessing the outside environment, thereby limiting occupations in the neighbourhood.

**A summary of my analysis of the restrictions imposed by the environment on occupation for these informants is given in table form.**

| CLASSIFICATION OF ENVIRONMENTS | | | | |
|---|---|---|---|---|
| | CULTURAL/ POLITICAL | ECONOMIC/ INSTITUTIONAL | PHYSICAL | SOCIAL |
| INDIVIDUAL | Culturally absorbed attitudes towards disability | | Severity of impairment and dependency on others<br>Little access to appropriate assistive devices | Low expectations of self now or for different future<br>Low self esteem<br>Feelings of loss of choice and control |
| HOUSEHOLD | Low expectations of how it could be as result of attitudes and beliefs | Poor financial stability | Very limited space in home<br>Difficult access to outside home | Not always consistent support to do things<br>Low expectations of family members |
| NEIGHBOURHOOD/COMMUNITY | Culture of gangsterism limits access | High rate of unemployment and generally limited occupational variety<br>Few resources eg libraries, clubs et | Unable to access neighbourhood without help<br>Lack of transportation | Avoids former friends<br>Stigma associated with disability |
| PROVINCE/ COUNTRY | | Financial constraints for implementation of policies | Policy, not yet legislation, in place but not enforced | Human Rights legislation does not encompass occupation and is not enforced |

#### 5.3.2.2.2 Financial constraints

Financial constraints impacted significantly on opportunities for occupational engagement.

Generally, the poor socio-economic conditions in the neighbourhood were obvious from observations of the environment. The surroundings in which the informants were living were dreary. Neglected house repairs, such as a boarded up window, peeling paint contributed to the generally depressed atmosphere.

All three informants were receiving state disability grants which "fall far short of the household subsistence level...." (White Paper on an Integrated National Disability Strategy, 1997). Two informants had paying boarders to supplement income. This required the sharing of rooms with consequent loss of privacy.

Occupational pursuits, besides watching television and listening to the radio were not supported in an environment where subsistence needs, that is feeding and clothing the family, had priority. The occupational needs of other members of the family had priority. For instance, for two informants, all the other members of the households were working or looking for work and this was deemed as a priority. This was epitomised by Willem: **" So I have to wait my turn".**

Igsaan declared that priority had to be given to basic health and his caregiver's needs before his own occupational needs. When he started to earn an income, his first purchases comprised equipment that supported his basic health needs and mobility (Jay

cushion and electric wheelchair, raised hospital bed). Only then was he able to consider his occupational needs (computer, an adapted van for transport and a paid driver).

The informants for this study did not have basic equipment to support their health-care and caregiver needs. Consideration could only thus be given to 'no cost' occupations such as being pushed down to the soccer field or hanging out in the game-shop, or to occupations shared by the family such as television and video viewing.

#### 5.3.2.2.3 Access to transport and assistive devices

Lack of access to transport was perceived to limit occupations both with and without family members and friends. Transport issues have been highlighted as one of the biggest limitations to accessing occupations outside the home. (White paper on Integrated National Disability Strategy, 1997). Of note, was not only the difficulty getting private transport by the informants, but also the difficulty getting in and out of the vehicle and the concomitant perceived caregiver burden. These served to act as deterrents to using the transport when it was available. Transportation of the wheelchair in the vehicle was also perceived as a limitation.

The informants of this study were all in receipt of low cost (government issue) assistive devices to support basic mobility needs and self feeding, but did not have access to anything which could support valued occupations, such as work tables or computers. Self propulsion indoors and independent mobility were not supported by lightweight manual adapted wheelchairs or electric wheelchairs (nor the space requirements for them). These limitations were imposed by the socio-economic circumstances of the informants and the financial constraints facing the health care system of the country. The

most appropriate wheelchair for the individual user are not readily available through the state tender system.

#### 5.3.2.2.4 Human and non-human support

Dependence on human support to do even the most basic tasks was verbalised by the informants as being an uncomfortable but necessary experience. However, an on-going thread throughout the interviews was a concern about lack of consistent and reliable support from the people in their environments. Plans for occupation were often discontinued in the fear that the support necessary for execution would not be available. The fear of being a burden and lack of finance or other means to make the arrangement a reciprocal one, resulted in the easier resolution - cessation of the occupation. A history of unreliable and inconsistent support from outside the family also led to feelings of resignation and low self worth.

Igsaan, although he now had access to financial resources to ensure that he could be in control over what he did and didn't do, verbalised that he too had limited himself in terms of engagement in valued occupations. Priority had to be given to basic survival and health needs first. He used Maslow's hierarchy of needs to explain this - satisfaction of basic survival needs of safety and shelter before self actualisation.

Resources which could ostensibly support people with disabilities, such as libraries, clubs, shops etc. were either seen by the informants to be unavailable or inaccessible due to transport problems.

#### 5.3.2.2.5 Future possibilities for alternative occupations are not obvious

Another contextual factor which served to limit vision for occupational possibilities for these informants, was their possible early deprivation, lack of learning and opportunity in an environment which did not develop their innate potential or expose them to a variety of occupations prior to their injury. Occupational profiles differ between the rich and the poor, the unemployed and employed, educated and uneducated. Level of education for all three informants was 10 years or less. Higher levels of education are not common in their communities where economic priorities often determined the need for leaving school to take up early employment. Incomplete secondary school education resulted in predominantly manual type employment, not only for these men but also throughout the community. Unemployment and poverty were common, as observed from all the adults on the streets during traditional work hours. Limited financial resources limited type and variety of occupations.

### 5.3.2.3 Unmet human needs and lack of challenge

Csikszentmihahlyi and Csikszentmihalyi (1988) regarded boredom and apathy to be the consequence of lack of challenge in a particular situation. The lack of challenge, in the lives of the informants of this study, was probably due to lack of expectation for them as disabled people to 'do' both at a personal and societal level.

Boredom is a sign of human needs not being met. According to Wilcock (1998: 144), it is the most common response to lack of satisfying and fulfilling occupation. In this instance, I would suggest that needs for satisfaction, purpose and meaning in daily occupations and routines are not met by largely passive inactive occupations such as watching

television or listening to the radio. Yet it is to these types of activities to which the informants of this study mainly had access.

This boredom is as much a consequence of lack of ability to impact one's environment, to access that environment and to make a meaningful difference (already discussed), as it is a consequence of not being able to actively 'do'.

Csikszentmihalyi, cited by Wilcock, 1998: 142), suggested that passive activity requires a low level energy expenditure, offers little challenge and that engagement in it to the exclusion of more active pastimes, may have as consequence "a mismatch between opportunities and abilities leads to a progressive atrophy of the desire for new challenges". This suggests an increasing apathy or passivity in pursuing a wider range of occupations that may offer greater challenge for inherent skills and abilities. The contextual obstacles, such as lack of finance, environmental inaccessibility, have already been discussed as limiting factors to a greater variety of more satisfying and challenging past-times.

### 5.3.3 Meaning and satisfaction in occupations

Occupation is recognised as having a basic role in creating, affirming, and experiencing meaning in life (Kielhofner, 1995: 60). The meaning experienced in occupations emanates from a variety of sources including the purpose and process of performing the occupation, a personal history of experiences and associations of the occupation, the actual experience of performing the occupation, and the socio-cultural definition of the occupation (ibid).

The notion of becoming carries with it connotations of development and growth. Fidler and Fidler (1978) spoke about 'doing and becoming', suggesting that the inherent drive to action, transformed into the ability to 'do' is fundamental to 'becoming' or to self-actualization. Implicit in this 'doing' to 'become' is the notion of meaning and purpose in what one does. Without meaning and purpose, the doing is unlikely to promote becoming. Hasselkus and Rosa (in Christiansen and Baum, 1997) felt that meaning in life is discovered through creativity, accomplishment and doing and by experiencing values of enjoyment, achievement and satisfaction with occupational performance (as part of doing and being). They felt also that it is necessary to be able to see potential and a future with possibilities (for becoming) to really discover meaning. Christiansen (1999) reinforced this with his hypothesis that individuals create their unique identities and life meaning through their occupations. The informants of this study were attempting to create meaning through the few things they could do. What was striking was the apparent improved life satisfaction experienced by Willem, who engaged in previously valued occupations and who showed some vision for his future. His being was enhanced by his active planning for future occupations. Igsaan, the key informant, similarly described greater life satisfaction as he planned and worked towards personal transformation.

### 5.3.4 Occupation contributes to meaning of life

As discussed, the men in this study appeared to be attempting to make some meaning of their lives, but their difficulties with engagement in meaningful occupations, served to make this an on-going struggle. To make sense of the tentative steps towards meaning-making, it seemed that it was necessary to explore features of their occupations and the opportunities and strategies for occupational engagement that seemed to support the process. The findings of this study of how occupation contributed to meaning in everyday

living, seemed to corroborate the findings of Rudman, Cook and Polatjko (1997) in their study of seniors' perspectives on activity (occupation). Occupation -

- **provided connection to other people and promoted a sense of belonging.**

Satisfaction was gained from the connectedness that occupation provided within the family. Possibilities were created in terms establishing a niche with its own unique contribution – doing schoolwork with the children ("***Dis my werk daai***"), doing activities with family and friends – watching television, going to the sport field.

- **contributed to organization of time.**

The informants used occupations to structure or pass the time in one sense, but also saw occupation as helping time pass more quickly. Of significance was the struggle to organise time sufficiently every day because of the paucity of occupations available to them with or without help.

- **provided some kind of continuity with the past, present and future.**

Occupations that could be continued albeit in a different form, were valued for the connectedness to others they continued to provide. Activities to keep in touch with what was going on in the present time in their communities pursued – watching out the window, talking to friends, listening to the news on television. Activities to look forward to were seen to provide a sense of pleasure (and disappointment) when they didn't happen – friends promising to pick Jon up to go to the soccer game, planning for his brother to take him to Cape Town

- **was valued for the means it provided to express and manage self identity.**

As summary of the discussion point (3.1.2), Willem, with his ability to see future possibilities for action that could support his emerging identity as a thinker and expert chess player/teacher, actively sought engagement in challenging occupations. Jon and Ronald with their limited perspective of future possibilities, not only from an occupational but a survival perspective, did not seem to find the same depth of meaning in their occupations. Their identities were defined only in terms of their disabled selves with very limited capacity to do anything.

- **provided stimulation in an otherwise monotonous day and week routine.**

For these informants, great variety was missing due to lack of resources to support occupations in their home settings. However, occupations that challenged and tested one's competence and skills were valued and contributed to positive feelings about self.

The informants recognised their own occupational needs which to a lesser or greater effect, they were trying to put into practice. The little ploys they used are described on pages 76 - 79, and so will not be discussed again.

Insights gained from the key informant, Igsaan, and from the literature (Reeve, 1998; Hurley, 1983; Thomas, 1994), highlighted additional points not made by the informants of this study, about the meaning of occupation in their lives. The most important of these was the need to have control and choice (provided by access to resources especially financial), and the importance of aiming for a realistic and achievable life goals, with little projects on the way to achieving them.

## 5.3 Implications for practice

This study provided a tentative conceptualisation of how occupation contributes meaning to the lives of young men with tetraplegia. The informants of this study had a limited daily repertoire of occupations that comprised primarily of passive type activities, with few opportunities for action or exercise of choice and control. Future possibilities for meaningful action and a supportive environment seemed to be the two major considerations inluencing the nature and meaning of their occupations. It would appear that the contextual factors, both pre- and post-injury limit the ability for future possibilities for action. This leads to apathy in exploring potential avenues for meaningful occupation thereby further limiting action. The consequence is boredom and an on-going definition of self as 'totally' disabled without ability to impact the environment.

Overall, it would seem that these men felt the paucity of occupation in their lives but felt relatively powerless to act because of the overwhelming contextual barriers, both perceived and real.

Numerous examples of contextual constraints that impeded the opportunity to pursue occupations of choice were given in the findings. On a more positive note, there was evidence that occupational strategies were being used to create meaning to a lesser or greater degree. Nevertheless, the overwhelming evidence of a daily experience of ocupational restriction needs to be addressed.

Implications for health professions and for occupational therapy are:

- Rehabilitation programmes need to directly address the self-defined occupational needs of their clients as early as possible in the rehabilitation process. This is especially urgent if one considers the consequences of occupational deprivation and inactivity – reduction in already reduced capacities, diminished self efficacy and a threatened self identity. Prolonged occupational deprivation may reduce the likelihood of adaptation (Whiteford, 2000) and potentially lead to increased occupational deprivation as the individual gets used to a restricted environment and increasingly reluctant to move beyond it. Occupational needs that are broader than activities of daily living, which are given such emphasis in early rehabilitation, can no longer be neglected in rehabilitation. The implication that therapy and rehabilitation must not be limited to assisting patients to adapt to the limitations of their disability or handicap, but that it should also focus on and support the individual's vision for the future, is supported by Johnson (1986). He maintained that "realistic expectations for any patient cannot be based solely on the therapist's experience but must include the patient's goals" (ibid: 757)
- Phenomenological methodology is useful to explore, for individuals from their own perspectives, what are their occupational needs and what are the personal, social and cultural restrictions to these. Both storytelling, with its present and past perspectives and story-making with its future perspective, may be useful data collection tools in preparation for improved understanding and goal setting in rehabilitation and in the longer term. Implicit to the future perspective, is active goal setting for a meaningful occupational life. An individual approach is needed for this because meaning in occupation is personally defined.
- This study has supported the premise that occupational deprivation is a known health risk factor (Wilcock, 1998), and as such needs serious consideration in relation to the environment in which the person with disability is likely to find himself

or herself. Prevention of occupational deprivation is an important strategy that supports the principle of "the pursuit of the goals of freedom from want, hunger, deprivation, ignorance, oppression, and exclusion should underpin strategies for disability planning" advocated in the Integrated National Disability Strategy (1997: 20). Poverty and incapacity puts a person at greater risk, because resources are limited and often financially out of reach. Since contextual factors are unlikely to change in the short-term, health promotion, from an occupational perspective, needs to take place at the level of the client together with his or her family and friends. This study showed the value placed in connectedness and belonging. This can be put to advantage in creating lived-in environments that provide greater opportunity for occupational engagement. Occupational enrichment needs to be explained and as far as possible pursued at an explicit level during rehabilitation with all the people in the immediate environment. While the National Rehabilitation Policy (1998) does not explicitly deal with the necessity for addressing the specific occupational needs of individuals undergoing rehabilitation, the results of this study can be seen as adding a further dimension to the principles underpinning rehabilitation services. Specific attention to occupational enrichment both at an individual and population level for 'at risk' individuals and communities, would facilitate, for disabled individuals, "integration and participation..... in the mainstream of community life" and foster a life lived with dignity and self respect, and provide opportunity for self-realisation (ibid: 5). Occupational needs should be actively addressed through in-depth counselling and education in the rehabilitation process.

- Contextual factors were highlighted in this study as major determinants of opportunity for occupation. Occupational therapists need to invest time and energy in influencing policy and monitoring implementation at social, cultural and political levels. Whiteford (2000: 204) proposes that occupational therapists embrace the

concept of "occupational justice", based on the individual's need to impact on the environment. If it is occupation that creates meaning in life and provides the potential for growth and personal transformation in major life transitions, then the lack of access to choice and variety of occupation should be viewed in the same light as lack of access to health and education. Strategies to improve mobility (which for the individuals in this study would be access to light-weight manual or electric wheelchairs), barrier free access, transport, education, employment and recreational opportunities for people with disabilities as advocated in the Integrated National Disability Strategy (1997) should improve access to occupational oppportunities.

## 5.4 Limitations of the study

The results of this study are not generalisable to the wider population due to its phenomenological nature. It has however demonstrated that exploration of a phenomenon from the person's perspective can contribute to an improved understanding of the nature and meaning of occupation.

The sample was small and opportunistic in keeping with the qualitative methodology. This was partly due to the time limitations imposed on the study and partly by the challenge of data collection from informants who were not accustomed to being asked to talk about themselves, their experiences and the meaning these had for them. I evaluated the quality of the interviews against four general principles advocated by Hollway and Jefferson (2000: 34), to arrive at the following insights:

- I should have used only open-ended not closed questions, the more open the better, and avoided 'why' questions which served to introduce concrete statements. My opening question was open but in a narrow sense, as it elicited an account rather

than meaning. However, it was chosen as a concrete way of tapping into the topic of occupations (using terminology easily understood by the participants) and to get background against which to establish rapport. My meaning frame may not have been clear, the topic seemingly mundane.

- *Eliciting stories may have been a more successful method for data collection than focussed interview.* I needed to continually refocus the informants on activities and occupations as the focus of the interviews, as other topics related to health problems, marital problems created by alcohol abuse in the family, expense and unreliability of personal care attendants, and to the actual illness experience were introduced. On reflection, I realised that this afforded me the opportunity to get a better understanding of the context that made or restricted opportunities for occupational engagement. I needed to consider that my informants all felt that their lives lacked anything worthwhile to talk about; everyday living was felt to be too mundane, and that they themselves did not consider themselves to be overly articulate.
- Although the purpose of the study was to gain understanding of the occupations of individuals with severe impairment from backgrounds different to my own to inform clinical practice, differences in class, race and gender may also have negatively impacted on the quality of the data.

In spite of these limitations, I feel that the study has revealed valuable insights.

## 5.6 Suggestions for future research

The themes that emerged from this study may contribute to developing theory through a grounded theory approach. Two key issues that warrant further study, are:

- The contribution of occupation to re-defining identity following sudden incapacity.
- Occupational enrichment and its link to health and well-being.

Since the contextual restrictions to engagement in meaningful occupation for the severely disabled person were subjectively highlighted in this study, it may be useful to do a more objective survey to assess the magnitude of the problem. The ICIDH-2 (International Classification of Functioning and Disability, 1999) as a classification of the consequences of health conditions, may be a valuable tool to gather quantitative data on the restrictions to participation in activities for people with disability at a personal level and in their own community settings. Results from such a study could provide strong evidence of the occupational restrictions and occupational needs for individuals with severe impairment. They could conceivably be used to motivate more strongly for development of policy and legislation supporting occupation as a basic human right.

## 5.7 Conclusion

This qualitative study has rendered some insights into the occupational lifeworld of three informants living with tetraplegia in relative low socio-economic circumstances on the Cape Flats. Their descriptions of a very limited opportunity for occupational engagement and limited occupational profiles contrasted sharply with the descriptions of themselves as 'doers' prior to their injuries. The loss of 'doing' resulted in a boring and dissatisfying lifestyle that did not support redefinition of a positive self identity or promote development and growth. A positive note was that, in spite of barriers – attitudinal, technological, accessibility and others – they all described some attempts at finding meaning in their limited occupations. The challenge is to address the occupational needs explicitly at the

level of individually defined goals, against a background of future expectations, and against a concerted effort to remove or modify barriers to participation at community level, to facilitate a difficult life transition. To do this, it is necessary to understand both purpose and meaning of occupation as defined by the individual. Occupational deprivation and imbalance need to be recognised for their role in poor quality of life. Occupational well-being deserves more attention in the rehabilitation process and in the day to day lives of people with disabilities who may be unable to easily engage in their chosen occupations.

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# ENDNOTES

# ENDNOTES

**English Translations of Afrikaans Quotes**

[1] When it rains and I'm sitting, and the sun is not shining, then I lie in bed for the whole day. I will just lie and watch TV for the whole day. Or I sleep the whole time. So I sleep the whole day. I will just wake up when they turn me, and then it is just sleeping. What else?

[2] I dream most of the time during the day that I'm now walking and that I'm now rich and that I have my own house. I think about these sorts of things, and that my friends come and visit. ...This morning I said I mustn't begin to think about these things; I must focus my mind on something else. ...It's been a long time that I think about things and nothing happens.

[3] It's a boring life this. It's really boring.

[4] I can't do anything

[5] I can't do anything now, it's really so, I can't do anything.

[6] Hands are very important. A person should be able to do things with his hands. Write, type, turn pages in a simple book. To turn one page takes me about two minutes. I will press the whole book against my stomach, ... turn and blow, blow and turn what I want and hope I get to the page I actually want. This is how I battle with simple ... the simplest thing.

[7] We were very sporty and every day, every day we could, we played and practised sport. It's hard for me now to just sit, because it's now nearly three years. I won't be able to adjust, I can't accept that this is how I am. I don't know how.

[8] They will always help me down, I mean, you can ride around wherever you like. I've been in this chair for three years now and I've never been to the Cape (Cape Town) again.

[9] And now the chair is making me feel so hopeless, and you are, how can you say, you can only expect bad luck, bad tempered and then you just take it out on anyone who is here. And I'm scared that I'm going to lose my friends if I'm like that, yes, if a person is so bad tempered. You don't know how to handle the situation. You're just bad tempered with anyone. So you're going to lose your friends.

[10] And even my girlfriend that I've got now. She and I went out together, uh, about nine or eight years ago, and then I got another girlfriend. And then, because I'm like this that girl dumped me, and now she's come back to me. I can't understand why she's here now. All this time I've had nothing to do with her, and now she's back. No. I can't understand it. Me, me I had no time for her, and, I mean it's not just any person who would come back to someone like me. Because look, now I'm in a wheelchair, and it's not because I'm normal that she's come back. Because I'm in a wheelchair.

[11] Um, my ratings (as a father), if I may use the English term, have diminished just a little. If they won't, if they won't do absolutely everything now that I ask or that I want, there'll always be some naughtiness going on behind my back, like what I, what the ..., that involves the children, just like any child is naughty if the father and mother aren't watching, they'll always be doing the wrong thing and so on. It is now out of my control and sadly I cannot do anything about it. It's something big (important) for me. Sometimes I feel so helpless, yes when I can't get close to them and give them a slap or two or a cuff on the ear.

[12] Now things have changed a lot. I'm used to it now, as you can see, I now have less time with them, and they see there is a change. Dad doesn't have much time. They come and talk and LE OP DIE KOOI. Sometimes when they are jumping on me, almost as if I'm a jumping castle, um, I can't do anything different. . I must make them satisfied on every side and not chase them away.

[13] And sometimes they play and if my friends are here, and they play with my friends, then I feel so sad that I'm like this. It is my job and I must be their father and play with them. Then I sometimes get jealous. It's not pleasant when you see someone else playing with your daughter. You also want to do it, but can't now.

[14] Well, ma'am, just as long as I can satisfy my wife, that is a comfort for me. ...Then I know another man won't come between us, mmm, and try to meddle or something. That is a possibility. But I try not to ever get jealous because it won't help anything.

[15] But the friends that I had are not my friends now. I now have other friends. The friends that I didn't worry about, they are the ones who come here now. ... No, they were friends of mine but I wasn't as close to them as I was with the others. I was surprised to see them coming here to me.

[16] I don't feel that I want to walk outside.. I just go down the road. I will just go here down to the corner and back again, because I don't feel like going there. I would rather go down to the game shop with my other friends DAAR AGTER, but the thing is I don't mix with everyone here. Old friends of mine that I don't much want to see, because they if they come here just walk past. So I, I just ignore them. Then I go in another direction in which I know I won't see them again or anything. It's better for me then. ... Then I avoid them. I'll only go to certain places.

[17] I, um, my dream that I really want to happen is that one day I'll get my legs back, that I'll be independent, that I'll get my hands back to be able to do things, and that I can pick my children up and cuddle and so on. That's very important for me. And naturally to be able to mess around in my garden again like I used to do. I just want to do things that I used to do. That's all.

[18] Those are all my dreams, but it's all for nothing. But I still think about it. Perhaps one day I'll still be able to get some small ordinary job.

[19] But if you don't have a job, and you live in the area, then you're going to belong to the gangs. Nothing to do, no money, nothing, and just to sit in the house the whole day. And when I do have to go out, if you don't belong to a gang, then they pressurize you and you have to join them.

[20] Well, it is a, it is something which I can't, it something that I can't actually, something that I just have to accept as a disabled person. I must accept the help of people, any people. ...It is hard, yes, that's right. I have to now unfortunately pocket my pride and now I even have to ask someone to wipe my nose with a handerkerchief, or to scratch my head when it itches, or my back that itches, or to empty my pocket because it's now time. Yes, or to ask, "Bring me water quickly."

[21] It would have been easier for me and easier for my girlfriend if she didn't struggle always to get me sitting in the chair.Every time she has to wait for someone else to help her put me in the chair and to turn me. I could have done things for myself and not have felt so dependent as I do now. If I want to go out now, I could have pushed myself, but now I can't.

[22] Otherwise I would be there a lot, although I can't play. But if someone doesn't come to fetch you, how can you get there? I can't ask my friends every day to come and fetch me.

[23] One just gets frustrated if something isn't done the way you want, but one gets used to the fact that there's no other alternative.

[24] If a person lies so long ... at the moment I'm lying cosy under my duvet and my second – what is that thing I lie on? – blanket. If I have to lie naked for 15 minutes, before someone dresses me, then I get irritated.

[25] I can't even make myself a cup of tea. When last did I drink a cup of tea? Because I can't hold it for myself, and if someone has to feed you, then it's always a quick process because you don't want the person to have to stand here with you for a long time ... then I drink just to finish quickly and that's not nice.

[26] Whenever it is really necessary for a decent / proper bath, then I have to be carried down to the bath which is already full. The water has already been let in, and then (I can) have a decent bath just like an ordinary person.

[27] Oh well, I'm used to the whole procedure.

[28] Like an ordinary person.

[29] But it's not actually pleasant for me on the field any more, because everyone looks at you and almost as if, yes, all right, a person is now crippled, but anyway, they look at you as if you come from outer space.

[30] Further I can't expect more out of life. In my condition it is, expectations limited.

[31] ...I'll probably not sit in the chair for very long, then I'll be back lying in the hospital again. And if I'm lying in the hospital again, then I know I'll never get out again. ... Many times I feel inside myself I can't live for long, because people in chairs don't live for so long.

[32] If I sit the whole day, sit alone in the house, I must say there is nothing else I can do....nothing, nothing to do, no money, nothing, and just sitting for the whole day in the house.

[33] There isn't a person every day and this person who was looking after me has jut got sick, and now she's not therre anymore and I don't know what's going to happen to me now, what lies ahead.

[34] Yes, well, if they aren't there, where do I go then? I don't want to go and sit in a home. It's not worth it to be there, because they don't look after you well there.

[35] Everyday you just have to lie there and wait for someone to come and look after you.....Yes, then I wait for my brother's daughter to come and help, but she doesn't come there every day. If she does come, then she comes very late.

[36] Then I cut out. Then they have to tilt me against the cupboard and then I come right if I sit like that for a short while. For about an hour or so, then I will come right.

[37] I am never alone in this house like I was in the Plain (in Mitchell's Plain). There is always someone who comes here.

[38] In Mitchell's Plain it is just me sitting there, or I go and sit just outside in the sun. There is no-one who comes to me. It is just my auntie and my uncle. See this, that is what happens every day for the whole day, and it's boring, and I get tired of it.

[39] The space is so small now. You can't go anywhere, but you must go only in this small area.

[40] I have been in the chair now for three years, and I have never been to the Cape (Cape Town) again.

[41] Everyone is busy and there are few people who actually have time for someone in a wheelchair.

[42] Most of the time during the day I dream that I am now walking and I am now rich and I have my own house. I think about these sorts of things, and that my friends come and visit

[43] It was always in the pipeline to study further in the four subjects to obtain my matric, and then to work my way up (the ladder). Because of circumstances I can no longer do that.

[44] At the moment there's no M-Net or a VCR or a colour TV here. But it's much better here for me. Friends are better than TV, because TV can't communicate with you – things don't talk back. But friends can talk back. Yes, it's better for me ... Yes.

[45] Outside, if I'm outside in the wheelchair, then I feel I'm now, I'm now stronger than when I'm in bed. I have more control ... because I can see from all sides. I can see who's coming, who's going out ...

[46] And then it is really to sit still and think deeply ... then a person values all the little things. Then you see what one takes for granted – the birds that come past to perch, or a dog or a child that walks past, watching you carefully, or even an aeroplane that flies overhead, and you look at it, and then you look at it and wonder how it stays in the air.

And such things.. It makes a deep impression on you. And so I realise now I took lots of things for granted, like the chirping of the birds, the growing of the plants and such things.

[47] It' better for me.
[48] For me it is not pleasant to sit at the soccer field. You really want to play and you can't. You just have to sit there and watch the others play. That's all I do at the field – Sit, sit.

[49] It's just to get out. It's better than sitting in the house like this. (It) takes away time. When I come back it's evening again; then I can just come and wash and go to sleep.

[50] I find that the more ... the more different activities or people I see, how much it brightens up my day. It's not so monotonous, you see, so boring.

[51] For me it is just all my things as usual.

[52] Everyone is busy and there are few people who actually have time for someone in a wheelchair. Naturally they just greet me. They should really stop and ask how it's going and so on and have a reasonable chat with me. But they'll just nod or greet me and then walk past.

[53] I feel shy.

[54] I still feel shy.

# APPENDICES

**APPENDIX 1A**

## Admissions to Spinal Cord Injury Unit at Conradie Hospital during 1999: Causes of injury

| | MVA | Stab | Gunshot | Fall | Rec/ Sport | Work-Related | Assault | Total Para/Tetra | |
|---|---|---|---|---|---|---|---|---|---|
| January | 6 | 3 | 8 | 1 | 1 | 0 | 0 | 14 | 5 |
| February | 5 | 8 | 3 | 2 | 0 | 0 | 1 | 10 | 9 |
| March | 7 | 5 | 5 | 0 | 1 | 0 | 1 | 8 | 11 |
| April | 10 | 1 | 2 | 0 | 2 | 0 | 1 | 8 | 8 |
| May | 9 | 2 | 4 | 1 | 1 | 0 | 3 | 9 | 11 |
| June | 6 | 3 | 3 | 0 | 1 | 0 | 1 | 2 | 12 |
| July | 6 | 4 | 3 | 1 | 1 | 1 | 1 | 6 | 11 |
| August | 13 | 0 | 1 | 0 | 0 | 0 | 1 | 8 | 7 |
| September | 2 | 8 | 5 | 2 | 1 | 0 | 0 | 10 | 8 |
| October | 8 | 6 | 3 | 1 | 0 | 0 | 2 | 10 | 10 |
| November | 5 | 1 | 1 | 1 | 0 | 0 | 0 | 3 | 5 |
| December | 14 | 11 | 8 | 1 | 2 | 0 | 0 | 19 | 17 |
| | | | | | | | TOTAL | 107 | 114 |

Figures by kind permission of Dr D. Newton, Conradie Hospital

Table 2

APPENDIX 1B

**Summary of residential areas of patients admitted to Conradie Hospital SCI Unit**

***Western Cape Metropole Region:***

| | C1-7injury | T1-L5injury |
|---|---|---|
| Bellville | 1 | 1 |
| Bishop Lavis | 1 | 2 |
| Bonteheuwel | 3 | 1 |
| Bridgetown | 2 | |
| Cape Town | | 1 |
| Connaught Estate | | 1 |
| Delft | | 5 |
| Durbanville | 1 | |
| Elsiesriver | 2 | 1 |
| Factreton | | 1 |
| Grassy Park | | 1 |
| Guguletu | 2 | 5 |
| Hanover Park | 1 | 4 |
| Heideveld | | 2 |
| Khayelitsha | 8 | 8 |
| Kraaifontein | 4 | 3 |
| Langa | 1 | 1 |
| Lansdowne | 1 | |
| Leonsdale | | 1 |
| Lotus River | 2 | |
| Maccassar | 1 | |
| Manenburg | | 3 |
| Milnerton | 1 | |
| Mitchells Plain | 5 | 6 |
| Montana/Belhar | 1 | 1 |
| New Crossroads | 1 | |
| Nyanga East | 3 | 5 |
| Ocean View | | 2 |
| Phillippi | 1 | 2 |
| Pinelands | | 1 |
| Ravensmead | 2 | |
| Retreat | | 2 |
| Sea Point | 1 | |
| Silwood Heights | 1 | |
| Strandfontein | | 1 |
| Surrey Estate | 1 | |
| Table View | 3 | |
| Valhalla Park | | 1 |
| Vasco | | 1 |
| **Total** | **50** | **63** |

***Areas highlighted fall on the Cape Flats***

Figures by kind permission of Dr D. Newton, Conradie Hospital

Table 3

**APPENDIX 1C**

**1999 Admissions to the Conradie Hospital SCI Unit per region in the Western Cape and outside the Western Cape.**

| | C1-7 injury | T1-L5 injury |
|---|---|---|
| **Western Cape** | | |
| Cape Town Metropole | 50 | 63 |
| West Coast / Winelands | 19 | 16 |
| Boland / Overberg | 13 | 8 |
| Southern Cape / Karoo | 12 | 10 |
| **Out of Province** | 15 | 10 |
| **Unknown** | 5 | |

Figures by kind permission of Dr D. Newton, Conradie Hospital

Table 4

APPENDIX 2

## Abbreviations and explanations of tests listed

**Measures of function:**

Barthel Index:
The index was developed to monitor functional independence before and after treatment, and to indicate the amount of nursing care needed. It can be used clinically to measure changes in function, and for research in adults with long-term problems such as strokes, spinal cord injuries, cardiac problems and amputations. It measures ten activities: feeding, moving from wheelchair and return, personal hygiene, getting on and off the toilet, bathing self, walking on level surface/ propel a wheelchair, ascend and descend stairs, dressing, controlling bowels, controlling bladder (Cole, Finch, Gowland, Mayo, 1995).

FIM (Functional Independent Measure)
This is an assessment of functional status. It forms part of the Uniform Data Set for Medical Rehabilitation (UDS). It can be used clinically as an outcome measure, and is useful to predict burden of care. It consists of 23 items in 7 areas of function: self care, sphincter control, mobility, locomotion, communication, social adjustment / co-operation, cognition / problem-solving (Cole, Finch, Gowland and Mayo, 1995).

**Measure of handicap:**

CHART (Craig Handicap and Assessment Reporting Technique)
A tool specifically designed to measure the level of handicap in a community setting, using the dimension of handicap in the World Health Organisation model of Impairment, Disability and Handicap. Test items were constructed to identify the degree to which respondents fulfilled the roles typically expected of able-bodied members of their society (Whiteneck, Charlifue, Kenneth et al, 1992)

**Example of a test with a Likert Scale**

SWLS (Satisfaction with life scale)
This test was designed as a measure of individuals' global judgement of their lives allowing respondents to weight domains of their lives in terms of their own values. It consists of five statements on a **7-point Likert Scale**, ranging from completely disagree to completely agree (Marcel and Dijkers, 1995)

APPENDIX 3

# TOESTEMMINGSVORM

Die studie wil 'n beter begrip kry van die alledaaagse aktiwiteite van jong mans met 'n spinale koord besering binne die konteks van hulle eie familie en die gemeenskap waar hulle woon.

Informasie sal hoofsaaklik deur middel van onderhoude ingesamel word. Onderhoude sal opgeneeem word met behulp van ‘n bandopnemer op ‘n tyd wat vir die deelnemer gelee sal wees, in die deelnemer se eie woning. Die bande sal nie met enige iemand anders gedeel word nie, behalwe die toesighouers van die studie en die tikster van die transkripsies. Die navorser sal al die bande vernietig na die voltooing van die studie. ‘n Videoband sal moontlik gebruik word om aktiwiteite binne die konteks van huislike onstandighede te illustreer om duidelikheid te verkry.

In die finale verslag van die studie sal sekere aspekte geillustreer word deur gebruik te maak van voorbeelde van die onderhoude wat gevoer is. Die deelnemer sal nie herken word nie, aangesien die deelnemer anoniem sal bly.

Die deelnemer hoef nie spesifieke vrae te beantwoord nie en kan ter enige tyd gedurende die onderhoude en studie onttrek.

Hiermee gee ek, (naam)……,
toestemming tot my deelname in die studie. Ek vestaan dat ek op enige tydstip kan onttrek van die studie en dat ek nie herkenbaar sal wees nie. Ek verstaan dat ek geen persoonlike voordeel uit die studie sal verkry nie. Ek is bewus daarvan dat die resultate van die studie aan my bekend gemaak sal word op navraag.

Aantekening van Deelnemer: ……

Aantekening van Navorser: ……

Datum : ……

# CONSENT FORM

**This study is aimed at getting a better understanding of the everyday activities of men with spinal cord injuries, within the context of their own families and the communirties in which they live.**

**Information will be mainly gathered through interviews which will be recorded on audiotapes. The interviews will be conducted at a time suitable for the research participant in his own home. The contents as is of the audiotapes will not be shared with anyone other than the supervisors of the study and the transcription typist. The audiotapes will be erased on completion of the study. A videotape may be used to illustrate activities within the context of the home to gain clarity.**

**In the final report for the study, certain aspects of the findings will be illustrated through the use of examples taken from the interviews. The research participant will not be able to be identified, as he will remain anonymous.**

**The research participant need not feel compelled to answer specific questions and may at any stage withdraw from the interview or research if he so wishes.**

**I, (name) ..... consent to participate in the study. I understand that I may at any time withdraw from the study and that I shall remain anonymous. I understand that I will not personally benefit from the study. I am aware that the results of the study will be made known to me on request.**

**Signature of Research Participant:.....**

**Signature of Researcher: .....**

**Date: .....**

## APPENDIX 4

### Summary of informants' details

Pseudonyms have been used.

| | Jon | Willem | Ronald |
|---|---|---|---|
| Age | 30 | 19 | 31 |
| Marital status | Partner | Single | Married |
| Dependants | 2 | Nil | 3 |
| Suburb | Elsiesriver | Bonteheuwel | Mitchells Plain |
| Accommodation type | Council flat, 3 roomed, second floor | 3 roomed, small kitchen and bathroom | 4 roomed, small kitchen and bathroom |
| Number of residents | 2 | 5 | 6 |
| Highest school standard | Std 8 | Std 6 | Std 8 |
| Previous avocational occupations | Sport, gangster | Sport, Sunday school teacher | Rugby, running gardening, family man |
| Previous employment | Busdriver (3 months) | Factory machine operator | Security officer |
| Present employment | Nil | Nil | Nil |
| Income source | Disability pension | Disability pension | Disability pension |
| Primary caregiver | Partner and male friend | Family members, APD care attendant one hour daily | Wife |
| Cause of spinal Cord Injury | Gunshot | Gunshot | Motor vehicle accident |
| Neurological level | C6 complete | C5 sensory incomplete | C 5/6 sensory incomplete |
| Duration of rehabilitation | 6 months | 6 months | 6 months |
| Hospital re-admissions since discharge | 2 : holiday relief, bladder surgery | Nil | Nil |
| Contact with support services | Community Health Centre Conradie Hospital | Conradie Hospital Community Health Centre APD | APD social worker Conradie Hospital |